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Telephone-based follow-up of children with epilepsy: Comparison of accuracy between a specialty nurse and a pediatric neurology fellow

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ABSTRACT

Background: Childhood epilepsy forms a significant burden on the health-care delivery system. Only a few pediatric neurologists available in most of the developing countries and caregivers face a lot of financial and logistic hardships, apart from a long waiting period for initial and follow up visits. Telemedicine is a proposed effective alternative in overcoming this burden.

Methods: Telephonic consultation by a pediatric neurology fellow was compared with that of a specialty nurse; both against face-to-face consultation (gold standard). Care-givers of children 4 months-18 years with epilepsy were telephonically consulted 24–48 hours before their scheduled hospital appointment by one specialty nurse and one pediatric neurology fellow at least 24 h apart in a random sequence. During the hospital visit, another pediatric neurology fellow blinded to the telephonic consultation, documented the same after Face-to-Face interview.

Results: In 141 children with epilepsy, 504 critical clinical events were identified. Telephonic consultation by pediatric neurology fellow had a sensitivity of 99 %, 97 %, and 100 % and specificity of 100 % each in detecting whether the child had any breakthrough seizure, any adverse event and whether the drug compliance was adequate or poor respectively, as compared to face-to-face consultation. Telephonic consultation by specialty nurse had a sensitivity of 91 %, 84 %, and 98 % and specificity of 97 %, 99 %, and 81 % in detecting whether the child had any breakthrough seizure, adverse event and whether the drug compliance was adequate or poor respectively. But the specialty nurses fared poorly in identifying atypical seizure semiologies like atonic and myoclonic seizures and documenting an exact number of breakthrough seizures, as well as few subjective adverse effects like behavioral abnormality and scholastic worsening, which was performed excellently by the pediatric neurology fellow.

Conclusions: Telephonic consultation in childhood epilepsy by pediatric neurology fellow has excellent sensitivity and specificity. A specialty nurse has also acceptable sensitivity and specificity in comparison with a face-to-face consultation.

1. Introduction

Telemedicine is the provision of health care services to a patient separated from the physician by a distance, with the help of information technologies and telecommunication [1]. In recent years, there is quick advancement of scope and usage of telemedicine in the field of neurology, also referred to as teleneurology. Beginning with acute stroke care, it is fast expanding to the care of persons with multiple sclerosis, Parkinson's disease, and epilepsy [2–6]. The two key factors driving the ever-increasing demand for telemedicine in Neurology are limited access to specialists (Neurologists) and difficulties faced by these patients while attending for face-to-face consultation [6]. As there are few pediatric neurologists in India and they are only available in large cities, most of the caregivers face a long waiting time, have to travel a large

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distance, face a lot of logistic difficulties, and often a lot of financial hardship also.

With nearly 5 million people living with epilepsy in India, the annual economic burden in our nation due to epilepsy amounts to 68.75 billion INR (1.7 billion USD). Out of the total cost incurred due to epilepsy in childhood, the parents have to bear the highest proportion in the first year after diagnosis, attributed to the hospital visit and diagnostic workup. The initial and follow up health care visit related costs account for approximately 80 % of the total expenditure, especially when the patient is referred to a tertiary care center and needs to be evaluated frequently at regular time intervals. A cheaper alternative for the same is the review of the child with epilepsy by the general practitioner/Pediatrician for the follow-up health care visits and only those with drug-resistant epilepsy and complicated seizure semiologies being referred to the pediatric neurologist at frequent intervals [7–10].

But it is often impossible in developing countries because of limited knowledge regarding standard treatment guidelines for epilepsy in general practitioners. Unlike the initial evaluation, during the follow-up visits most stable epilepsy patients do not require extensive clinical and diagnostic evaluation or major modification of antiepileptic drugs. In such scenarios, a tangible solution to reduce health care visit related time, and the cost is to employ telemedicine by specialty nurse trained in dealing with epilepsy cases. This has the potential to reduce the health care visit related costs of the patients, waiting period to get an appointment of a busy pediatric neurologist and also the work-load on already over-burdened specialists. If successful, it has the potential to judiciously redistribute the working hours of epilepsy specialists towards the care of relatively more complicated cases. As the follow-up visits of children with epilepsy after the initial evaluation is predominantly based on parents' reporting of symptoms and drug compliance, they are also not likely to be compromised in the quality of care [3–6]. However, diagnostic studies with adequate sample sizes are needed to determine whether telephone consultation by specialty nurse can be an equally effective alternative to face-to-face consultation (the gold standard for follow-up care) in stable childhood epilepsy patients. The present study was designed for similar motive to compare the diagnostic utility of telephone consultation by a trained specialty staff nurse with that of a pediatric neurology fellow; both against the face to face consultation by another pediatric neurologist (gold standard) to accurately identify critical clinical events in children with epilepsy.

2. Material and methods

This prospective follow up study to compare the diagnostic accuracy of telephonic consultation by specialty nurse and pediatric neurology fellow was carried out in the Department of Pediatrics, All India Institute of Medical Sciences, New Delhi, over two years from November 2016 to March 2018. All the patients were enrolled from pediatric neurology specialty clinics, run exclusively by qualified pediatric neurologists, after informed consent from the caregiver. Ethical approval was taken from the institutional ethical committee before the commencement of the study.

The main objective of the study was to compare the diagnostic accuracy of telephone consultation between a trained specialty nurse and a pediatric neurology fellow to identify any critical clinical events as compared with the face-to-face consultation (gold standard), in children with epilepsy aged 4 months to 18 years. The secondary objective was to compare the diagnostic accuracy between both groups to identify critical clinical events in terms of assessment of spasticity/dystonia, development (gaining, static, regressing), feeding problems, vision, hearing problems, contractures, and bedsores, drug adverse events, drug noncompliance, seizures, features of raised intracranial pressure and other adverse events.

Confirmed cases of West syndrome (based on standard internationally accepted criteria) were enrolled only if 12 weeks of ACTH/Steroid/Vigabatrin therapy has been completed. Confirmed cases of Lennox Gastaut syndrome, primary generalized epilepsy, juvenile myoclonic epilepsy, childhood absence epilepsy, and other defined electroclinical syndromes were also included in the study. Children with Neurocysticercosis and seizures were enrolled in the study only if they had up to 5 lesions on neuroimaging, were not receiving cysticidal therapy at the time of enrolment (e.g. calcified granuloma) or had completed cysticidal therapy. Children with West Syndrome before completion of 12 wks of ACTH/ Steroid/ Vigabatrin therapy, children with Lennox-Gastaut syndrome (LGS) who have not undergone initial etiological evaluation, complicated Neurocysticercosis cases (with >5 parenchymal lesions, intraocular and intraventricular) were excluded. If the primary caregiver was not available during the consultations in the initial visit, then the cases were also excluded.

2.1. Operational definitions for study

For the study, critical clinical events were defined as those related to the disease course or drug therapy occurring during epilepsy management. These included lack of compliance with AED dose/regimen, seizures, features of increased intracranial pressure, AED related, and other adverse events including excessive sleepiness, irritability, neurological deficits, and infections. Presence of one or more of the following was considered as the drug-related adverse event: skin rash not associated with fever, dizziness, and vertigo, recent-onset imbalance while walking, standing or sitting

Drug non-compliance was defined as either not taking the prescribed anti-epileptic drug or taking drugs other than the prescribed drug, taking the amount of drug that is insufficient or excessive, or taking the drug at incorrect intervals than the prescribed frequency. Raised intracranial pressure was defined as the presence of any two of the following: headache, irritability, excessive drowsiness, blurred vision

2.2. Study procedure

The children with epilepsy, aged 4 months to 18 years, of either sex with access to telephonic services attending the pediatric neurology clinic were assessed for eligibility and were enrolled. The partially filled disease-specific proformas (including demographic details, clinical diagnosis, and treatment details like name of AEDs, prescribed dose, and frequency) were handed over by the principal investigator to the trained specialty nurse, Doctor A (the Pediatric Neurology fellow) for independent telephone consultations and Doctor B (the Pediatric Neurology Faculty) for a face-to-face consultation. The Pediatric neurology nurse, doctor A, and doctor B were blinded to each other's assessment.

2.3. Telephonic consultation

Every week, the specialty staff nurse and the pediatric neurology fellow conducted telephone consultations on specified day and time (48−72 hours before scheduled hospital visit) which was intimated to the parents/guardians of the patients at the time of enrollment. Both the telephone consultation used to occur at a gap of 24 h. One group of patients was called by trained specialty nurse followed by the pediatric neurology fellow and the reverse direction was followed in the other group. During the hospital visit, the enrolled patients were interviewed by doctor B (pediatric neurology faculty, gold standard). The consultation included a structured pre-designed questionnaire for documenting critical clinical events. This Questionnaire was disease-specific with separate proformas for children with the West syndrome and LGS, primary generalized epilepsy (PGE), and neurocysticercosis.

2.4. Face-to-face consultation

After the telephone consultation, the specialty nurse used to write the summary of consultation as either "*Needs face-to-face consultation*" (if any of the critical clinical events were identified) or "*Does not need face-*

to-face consultation" (if none of the critical clinical events were identified). At the end of the consultation, the parents were requested to attend the hospital as per the appointment. A similar telephone consultation was made by doctor A (pediatric neurology fellow). He/she also used to write the summary of consultation in the same way.

The face-to-face consultation was conducted by the pediatric neurologist in the next visit. It was considered as the gold standard for evaluating the diagnostic accuracy of telephone consultation. This consultation used to be comprehensive and used to include parental interviews and detailed physical examination.

2.5. Training of the pediatric neurology nurse for telephone consultation

The specialty staff nurse was trained for identifying various seizure forms, critical events, and comorbid problems in children with epilepsy before the commencement of the study. She was also trained regarding the technique for a telephone interview, contents of the predesigned study proforma, and instructions for filling the proforma during telephone consultations. The same nurse had prior experience of >10 years in dealing with children suffering from neurological disorders including epilepsy. She was a full-time nurse in the Child Neurology Division at the study site and used to dedicate the whole of working hours dedicatedly towards childhood neurological disorders only.

2.6. Training of the Doctors for telephone consultation

The Doctors (pediatric neurology fellows) to be involved in the study were trained about the interview technique, contents of the proforma, and instructions for filling the pre-designed proforma for telephone consultations.

2.7. Sample size estimation and statistical analysis

Considering a maximum difference of 5% in the diagnostic accuracy of telephone consultation between trained specialty nurse and pediatric neurology fellow necessitating face-to-face consultation, the number of critical events diagnosed by the gold standard should be 455. However expecting a sensitivity of 90 % for the telephonic consultation compared to face-to-face evaluation, the overall sample size in terms of critical events comes out to be 500. Absolute and individual specificity, sensitivity, positive and negative predictive values, and likelihood ratios of telephone consultation by a specialty nurse and a pediatric neurology fellow to identify any critical clinical events were calculated using SPSS software version 23.0 and were expressed in terms of percentage with 95 % confidence interval. Likelihood ratio were expressed as the proportion with 95 % confidence interval. Appropriate statistical tests were used to determine whether the difference between the two variables was statistically significant. A P-value of less than 0.05 was considered statistically significant.

3. Results

During the study period, a total of 141 children were enrolled and a total of 504 critical clinical events were identified. Baseline demographic characteristics of the sample population have been described in Table 1. The epilepsy characteristics, including neuroimaging and EEG findings, have been described in Table 2. Type of critical clinical events including breakthrough seizures and adverse effects and efficacy of pediatric neurology fellow and specialty nurse to identify these critical clinical events have been described in Table 3. Sensitivity and specificity to identify different critical clinical events have been demonstrated in Table 4.

Out of the 141 children enrolled, 135 (95 %) completed telephonic consultation and later face-to-face consultation. A total of 133 (94 %) caregivers were satisfied with the advice provided in telephonic consultation. A total of 71 (50 %) children had some critical clinical events. The breakthrough seizure occurred in 47 (33 %) children, while some adverse effect occurred in 38 (26 %) children, but all these adverse effects were WHO grade 1 and 2 and none of them were serious or life-threatening. Most of the participants had structural epilepsy (113, 80 %), with abnormal MRI brain and EEG, while more than half (76, 53 %) had perinatal adverse events including birth asphyxia. Most children (125, 89 %) were on one or two antiepileptic drugs and only a few (16, 11 %) were receiving more than two drugs at the time of enrollment. The majority of children also had various co-morbidities including spasticity, developmental delay, intellectual disability, dystonia, and behavioral abnormalities, etc. But none of the children were found to have significant worsening of these co-morbidities to raise medical concern at the

Table 1
Baseline demographic and clinical variables of the sample population.

Clinical variable	Frequency (n = 141)
Male	95(68 %)
Female	46(32 %)
Age (mean, SD)(in years)	10.21 ± 3.93
Loss to follow up	7(5%)
Study completed	135(95 %)
Caregiver satisfaction with teleconsultation	133 (94 %)
Number of children with critical clinical events	71 (50 %)
Total no. of critical clinical events	504
Co-morbidities	
Global developmental delay/ intellectual disability	63(44 %)
Spasticity	20(14 %)
Dystonia	6(4%)
Behavioral abnormality	33(23 %)
Sleep disturbance	13(9%)
Secondary nocturnal enuresis	5(3.5 %)
Constipation	8(5.6 %)
Swallowing dysfunction	27(19 %)
Vision impairment	18(12 %)
Squint	9(6%)
Contractures	2(1.5 %)

Table 2
The epilepsy characteristics, including neuroimaging and EEG findings of the sample population.

Epilepsy variables	Frequency (n = 141)
Baseline seizure frequency (mean, SD) (per year)	4.17 ± 1.89
Abnormal EEG	127(90 %)
Abnormal MRI brain	113(80 %)
Number of AEDs (mean, SD)	1.89 ± 0.73
Number of patients on 1 AED	66(46 %)
Number of patients on 2 AEDs	59(41 %)
Number of patients on 3 AEDs	11(7.8 %)
Number of patients on 4 AEDs	5(3.5 %)
Phenytoin	57(40 %)
Valproate	73(51 %)
Levetiracetam	40(28 %)
Benzodiazepine	75(53 %)
Oxcarbazepine	20(14 %)
Topiramate	2(1.4 %)
Zonisamide	5(3.5 %)
Lamotrigine	1(0.7 %)
Vigabatrin	4(2.8 %)
Focal seizure 70	70(49 %)
Generalized seizure	81(57 %)
Both generalized and focal seizure	17(12 %)
Myoclonic seizure	3(2.1 %)
Atonic seizure	3(2.1 %)
Absence seizure	1(0.7 %)
Perinatal hypoxia sequelae	76(53 %)
Traumatic brain injury sequelae	3(2.1 %)
Neurocysticercosis	17(12 %)
Focal cortical dysplasia	3(2.1 %)
Lennox Gastut syndrome	12(8.5 %)
Previously West syndrome	8(5.6 %)
BCECTS	5(3.5 %)
Primary generalized epilepsy	23(16 %)

Table 3
Type of critical clinical events including breakthrough seizures and adverse effects and efficacy of Pediatric Neurology fellow and Specialty Nurse to identify these critical clinical events.

	Numbers diagnosed on a face-to-face interview	Numbers detected by Pediatric Neurology DM resident	Numbers detected by specialty Nurse	P-value
Children with critical clinical events (seizure and/or adverse event)	71	70(98 %)	65(92 %)	0.10
Children with break through seizures	47	47(100 %)	46(98 %)	0.33
Break through seizures	453	450(99 %)	360(79 %)	0.0001
Generalized tonic clonic seizures	172	172(100 %)	167(97 %)	0.02
Focal clonic seizures	113	113(100 %)	108(95 %)	0.01
Focal tonic seizures	67	67(100 %)	62(92.5 %)	0.0001
Myoclonic seizures	53	51(96 %)	12(22 %)	0.0001
Atonic seizures	48	47(98 %)	11(22 %)	0.0001
Children with adverse events	38	37(97 %)	32(78 %)	0.002
Adverse events	51	50(98 %)	38(74 %)	0.0005
Excessive sleepiness	18	18(100 %)	17(94 %)	0.29
Worsening of scholastic performance	12	12(100 %)	8(66 %)	0.03
Behavioral abnormalities	15	14(93 %)	9(60 %)	0.0001
In-coordination	3	3(100 %)	2(66 %)	0.31
Gastrointestinal intolerance	3	3(100 %)	2(66 %)	0.31
WHO grade 1 adverse effects	45	44(97 %)	32(71 %)	0.0008
WHO grade 2 adverse effects	6	6(100 %)	6(100 %)	–

next follow-up visit, probably due to the small time interval between two visits (1–3 months).

The pediatric neurology fellow performed excellently in all aspects, in diagnosing the children with breakthrough seizure, semiology and number of breakthrough seizures, children with adverse events, nature of the adverse event, and compliance, with sensitivity and specificity for all of these being >90 %. The specialty nurse although lagged behind the pediatric neurology fellow in almost all of these prospects, probably because of difference in depth of knowledge between them, however, they were able to identify which of the children had a breakthrough seizure ($p = 0.53$) or critical clinical events ($p = 0.10$) and whether they are compliant with the drug therapy or not ($p = 0.46$).

Both the sensitivity and specificity of specialty nurse was >80 % for detecting the above three parameters and also for detecting generalized/focal tonic/clonic seizures. But the specialty nurse fared poorly in identifying other semiology of seizures including myoclonic and atonic seizures and they also underestimated the number of breakthrough seizures, especially for myoclonic and atonic seizures, although it did not change the treatment decision in the majority of patients. The specificity of specialty nurse in identifying the nature of the adverse event was acceptable (81 %), although they were not sensitive and missed some children with WHO grade 1 adverse effect. But they correctly diagnosed all the 6 children with relatively more severe WHO grade 2 adverse effects and only these adverse effects have therapeutic implications. Overall, in some areas of comparison, the telephonic evaluation by specialty nurse fell quite below that of the physician.

4. Discussion

It is the first study of its kind which has compared the efficacy of pediatric neurologist and specialty nurse in epilepsy telemedicine, as compared to face-to-face consultation. This is the first study in existing literature, which has identified critical areas in which specialty nurses fared poorly in telemedicine like atypical seizure Semiology and relatively mild subjective adverse effects. This study demonstrated that telephonic consultation by pediatric neurology fellow in well-controlled childhood epilepsy has excellent sensitivity and specificity to identify critical clinical events. Although the specialty nurse lagged behind the pediatric neurology fellow in the study, it can be explained by the level of training and knowledge difference between both the groups. It is noteworthy to mention that even the specialty nurse was able to identify most of the events requiring immediate medical concern like whether a breakthrough seizure or a severe adverse effect has occurred. Undeniably, they were not able to identify rare seizure semiologies like myoclonic and atonic seizures, the exact number of breakthrough seizures, and other highly precise information. But it can be explained because of the degree of command they have over epilepsy, which is less than the pediatric neurology fellow. Still, sensitivity and specificity of around 80 % for the majority of clinically relevant parameters for the specialty nurse in resource-constrained settings can be accepted due to the limited availability of trained pediatric neurology fellows in a developing country like India.

Table 4
Diagnostic accuracy variables to identify different critical clinical events in telephonic consultation by Pediatric Neurology fellow and specialty nurse.

	Person conducting a telephonic interview	Sensitivity	Specificity	Accuracy
Detection of children with critical clinical events	Pediatric Neurology Fellow	98 %	100 %	99 %
	Specialty Nurse	91 %	97 %	94 %
Detection of nature critical clinical events correctly	Pediatric Neurology Fellow	98 %	100 %	98 %
	Specialty Nurse	79 %	75 %	78 %
Detection of children having/not having breakthrough seizure	Pediatric Neurology Fellow	100 %	100 %	100 %
	Specialty Nurse	97 %	100 %	99 %
Detection of nature of seizures correctly	Pediatric Neurology Fellow	99 %	100 %	99 %
	Specialty Nurse	79 %	82 %	76 %
Detection of generalized/focal tonic/clonic seizures	Pediatric Neurology Fellow	100 %	100 %	100 %
	Specialty Nurse	95 %	81 %	92 %
Detection of myoclonic/atonic seizures	Pediatric Neurology Fellow	97 %	100 %	97 %
	Specialty Nurse	22 %	97 %	21 %
Detection of children having/not having adverse event correctly	Pediatric Neurology Fellow	97 %	100 %	99 %
	Specialty Nurse	84 %	99 %	95 %
Detection of nature of adverse events correctly	Pediatric Neurology Fellow	98 %	100 %	99 %
	Specialty Nurse	74 %	98 %	90 %
Detection of compliance	Pediatric Neurology Fellow	100 %	100 %	100 %
	Specialty Nurse	98 %	81 %	97 %

4.1. Previous studies on telemedicine in epilepsy

Some studies have established the safety and effectiveness of telephonic consultation by doctors in diagnosed adult cases of epilepsy,

although similar studies in children are less. Previous studies have shown that telephonic follow up is more effective and similar to face-to-face consultation in follow up cases of epilepsy as compared to cases with new-onset paroxysmal events, where the characterization of semiology of the event is prerequisite before taking treatment decision. Currently, with the advent of short message services, WhatsApp audio, and video messages, and video calling facilities, these restrictions can be circumvented. In children, however, often the semiology of seizures is atypical such as epileptic spasms and myoclonic, atonic seizures, and many times children are unable to describe the aura symptoms. Thus, telephonic consultation for epilepsy in children poses additional challenges [8,10].

Most children with epilepsy reside in low- or middle-income countries (LMICs) where there is the scarcity of doctors and the majority of epilepsy cases are inadequately managed or even remain undiagnosed and untreated altogether. In recent years many novel models like our study have been proposed to explore paramedical health care professionals as non-inferior alternatives for services not requiring complicated medical or surgical skills [11–13].

Bahrani et al. [14] in a randomized controlled trial involving 465 stable epilepsy patients demonstrated that there was no difference between the proportion of patients with breakthrough seizures and the total number of breakthrough seizures between the patients with face-to-face consultation and who have been reviewed telephonically, like our study. Thus they concluded that neurologists may revert to telephonic review in selected stable epilepsy patients, without compromising the quality of care. In developing countries like India, the secondary treatment gap for epilepsy patients with remote access to doctors can be effectively reduced, as telephonic review required less time consumption on part of the patient (10 min vs 22 h) and less expansive by INR 865. They recognized in their study the huge underlying potential of telephonic review to effectively reduce the secondary treatment gap for millions of patients with no easy access to doctors. The loss to follow up was more in the face-to-face consultation group. More than 90 % of cases were satisfied with the telephonic review.

At the current study site in 2011, Konanki et al. [15] successfully evaluated the diagnostic accuracy of telephone consultation to accurately identify the critical clinical events in 228 children with Neurocysticercosis. The telephone consultation had a sensitivity of 92.7 %, a specificity of 97.6 %, an NPV of 99.6 %, a PPV of 66.2 %, a positive likelihood ratio of 38.6 %, and a negative likelihood ratio of 0.07 to identify these critical clinical events.

4.2. Previous studies on telemedicine in epilepsy by the nurse

Previously also few clinical studies have been carried out to explore telephone nursing in children with epilepsy. The telephone nursing line has been shown to be an alternative for the shortage of subspecialists like pediatric neurologists in a study by Letourneau et al. [16]. This study examined the use of a telephone nursing line for triage in a hospital-based pediatric neurology clinic. It concluded that most telephone calls and most long telephone calls were related to children with epilepsy. Nurses could manage more than half of all telephone calls without physician assistance. The authors concluded that the use of a nursing line can help the doctors to allot more time and better care to complicated patients.

Bingham et al. [17] in 2007 demonstrated the acceptability and sustainability of telemedicine-enabled nurse-led epilepsy service. In the model devised by them, the nurse specialist used to travel to the patient's local hospital in place of the neurologist. After assessing the case, if the nurse specialist used to contact the neurologist if problems were requiring his expertise. The neurologist again used a video link with the patient and nurse, when he was not able to resolve the issue by audio call. After five years of operating at maximum capacity, a patient satisfaction survey showed 72 % of patients were satisfied with the telephonic consultation by the nurse and 90 % opted to revisit the telephonic consultation service again in the future. After this study, the investigators switched two-third of their patient load to the nursing specialist, supplemented by telephonic consultation and there were obvious savings in cost-benefit analysis.

Rajbhandari et al. [18] demonstrated the safety and efficacy of one such model aimed at training local residents in a rural district of Nepal as epilepsy health workers (EFWs) in 2018. In any person presenting with a paroxysmal event, the EFWs used to contact the epilepsy specialist telephonically, when the probability score of the event being epileptic in a smartphone-based application was above a cut-off. The EFWs subsequently used to arrange antiepileptic treatment if it was considered to be indicated by the specialist. Within 18 months study period, 112 persons with epilepsy were included in that study. There was 93 % diagnostic agreement with face-to-face consultation, seizures stopped altogether in 33 %, reduced in frequency in 57 % and only 5% had adverse effects. Around 96 % of patients were satisfied with this service rather than traveling for a conventional face-to-face visit with the doctor.

In another novel combined Nurse Practitioner–physician team care model proposed in 2017 by Hill et al. [19] in the USA, there was the increased availability of clinic appointment slots for epilepsy care, along with the delivery of improved quality of care. This novel care model demonstrated equivalent clinical outcome and adherence for the epilepsy care quality measures, superior adherence in providing personalized epilepsy safety education, counseling measures regarding query for side effects, and screening for behavioral co-morbidities, as compared to the traditional physician-only care model.

Role of Epilepsy specialist nurses (ESNs) was first recognized in the UK in 1988, but much of existing knowledge on their clinical expertise is based on anecdotal evidence only, due to dearth of well-designed trials. ESNs are the leaders of service improvements and change (SENsE study) from Ireland by Higgins et al. [20] in 2018 demonstrated that the ESNs act as key players in leading changes within epilepsy services, in public epilepsy education of the public, and the continuous improvement of epilepsy care. This study included 12 ESNs, 24 multidisciplinary team members, and 35 peoples suffering from epilepsy. ESNs were found to bring change by participating in the following key areas: initiating the development of new clinical practices, designing educational programs and resources for patients with epilepsy, family and the public and building capability involving the multidisciplinary team.

Based on this study results a 24 × 7 toll-free tele-helpline number was launched in April 2018 in our center manned by Pediatric Neurology Nurses, who provide telephonic advice in consultation with Pediatric Neurology Fellows and it has been extremely helpful during the current COVID-19 pandemic time for our epilepsy patients.

Source of funding/ support

None.

Disclaimers

Nil.

Conclusion

Telephone consultation by specialty nurse has acceptable sensitivity and specificity for diagnosing breakthrough seizure and drug-related adverse events as compared to pediatric neurology fellow and face-to-face consultation.

Transparency document

The Transparency document associated with this article can be found in the online version.

Declaration of Competing Interest

None.

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