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Original Article

Feasibility of Telemedicine for Follow up of Children with Established Seizure Disorder- A Tertiary Care Center Prospective Study

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Abstract

Introduction: Medical information exchanged via electronic communications to improve a patient's clinical health status by a physician without in-patient visit is telemedicine. Control of seizures with antiepileptic drugs, reassurance for compliance to drugs, regular monitoring of adverse effects of drugs in patient with established seizure can be possible through telemedicine. The main objective of this study was to evaluate feasibility of telemedicine for follow up of children with established seizure disorder.

Methods: This study was conducted among children of age one to 16 years with an established seizure due to any cause presenting to the Paediatric Neurodevelopmental OPD of Tribhuvan University Teaching Hospital (TUTH) between October 1, 2018 and September 30, 2020. Mobile phone as a modality of telemedicine was used to inquire about seizure every month for 12 months and whenever necessary.

Results: When parameters as seizure control, total cost and time spent per hospital visit, distance to TUTH were analyzed, more than 75% caregivers were satisfied with telemedicine. Greater age, appropriate development, focal onset of seizure, normal electroencephalogram and seizure adequately controlled by single antiepileptic drug were the favorable factors in better seizure control in children using telemedicine.

Conclusions: Telemedicine for follow up of children with established seizure disorder seems to be a feasible and satisfactory option when implemented with caution and proper patient selection as it decreases unnecessary high expenses and time to hospital visit

Introduction

Exchange of information by various means of technologies such as internet access with mobile phones has significantly affected all sectors of society including medical sector.[1,2] Telemedicine is the use of medical information exchanged from one site to another via electronic communications to improve a patient's clinical health status and it comprises utilization of telecommunication applications and technologies such as virtual two-way live or streaming video, videoconferencing, smart phones, etc.[3]

Telemedicine has been enormously implemented in various sub-specialties of medicine. Use of mobiles phones and its various applications, also called as mobile health (m-health), are some of the widely used means of communications.[1,4,5] Telemedicine improves the access of patients with chronic disease such as seizure residing in rural

areas to neurologist and treating physician in tertiary care centers providing opportunities to save time and money.[6,7]

The lack of access to proper neurological care is a significant problem in low to middle income countries.[8] Telemedicine is next available option in these situations. It has become a convenient tool for medical care as they are increasingly being used for immediate seizure control or detect any new changes in pattern of seizure, alter dosing of antiepileptic drug (AED) and even counseling patients about advanced diagnostic and therapeutic options.[9,10] So the aim of the present study was to analyze feasibility of telemedicine for follow up care of a child with established seizure disorder.

Methods

The study was done in Paediatric Neurodevelopmental OPD of Tribhuvan University Teaching Hospital (TUTH) which is a tertiary care hospital in Nepal. The study was commenced after getting approval from the Institutional Review Board. After obtaining informed consent from primary care taker, 115 children with established seizure disorder fulfilling inclusion criteria were consecutively enrolled from October 1, 2018 to September 30, 2019 and followed for one year. Demographic details of case, relevant information for seizure control, physical examinations including developmental assessment etc were documented. Investigations such as MRI, CT of head, EEG, metabolic profile etc. were done where indicated and recorded. Any mobile phone including a smart phone with various applications which the caretaker of the child was able to use to provide information was used. The telemedicine consultation data were maintained as per American Telemedicine Association operating procedures for pediatric telehealth.[11] Children aged from one year to 16 years with established seizure disorder were enrolled consecutively provided the care givers were able to communicate satisfactorily with the use of phones for the treatment. The selection or continuation of particular AEDs were based on International League Against Epilepsy (ILAE) 2017.[12] A detailed plan was made regarding seizure medications including drug titration, possible side effects, plans for breakthrough seizures, tapering of drugs etc for each child.[13] The children were asked for follow up in person every six months. At the end of six months and 12 months of follow up calls, care taker satisfaction to telemedicine were analyzed according to Likert scale.[14] At the end of the study they were also asked whether they would recommend such type of telemedicine to others. Caregivers were explained about recruitment process and that they would be called by phone once a month on same consecutive recruitment dates for one year. Caregivers were also told to contact whenever child has seizure or need physician advices. They were free to bring the child for an unscheduled clinic visit at any time to the hospital or any other health care institution for seizure as well as any medical conditions. Response to mobile call was classified as picks up, does not pick up more than six times in a year, switch off / cannot be reached at the moment more than six times in a year, and loss to follow up if not contacted even once. Expenses including transport costs, lodging cost, food expenses, OPD ticket costs were calculated as cumulative expense cost and was done from the caregiver' perspective. Job leaves or income loss for a parent or escort were not included in cost analysis. Economic status of parents of child in the society was classified based on Kuppuswamy Scale for 2019.[15] Time spent on hospital visit (travel time to reach hospital, waiting time to consult treating physician who is a researcher, time spent while consultation), missed school days for child, were also recorded. Family social burden due to child's condition were also documented. Data was entered in SPSS 20 version for statistical analysis. The main outcomes analyzed were seizure control and caregiver's satisfaction. Based upon seizure frequency, patients were categorized as follows:[10]

Controlled: No seizure or only one episode of seizure in one year study period

Uncontrolled (Active): Two or more seizure episodes in one year study period.

Results

Total 115 children were enrolled for the study. The study included children from one year to 16 years of age with mean age of 8.21 years. Almost all patients were from middle class or lower class as per modified Kuppuswamy Scale 2019. The telephone call attendance were as described in the study flow chart (Figure 1) below.

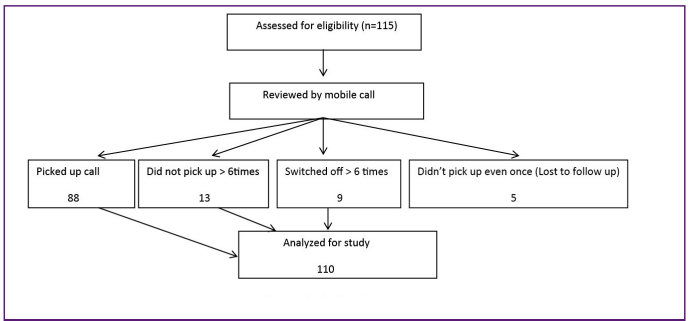

Figure1 Study flow Chart

Those who couldn't be contacted on a scheduled monthly call were inquired about seizure control of previous month as well during the follow up monthly call. Those who were regarded as lost to follow up in telemedicine however did come for follow up visit in hospital during study period. Caregivers whose mobile were switched off or considered as loss to follow up gave reasons for not receiving the call as mobile being lost, mobile damaged, could not recharge due to financial issue, SIM card being changed, mobile network issue in residing village etc. Among 110 children, 69 were boys and 41 girls. Fifty four (49%) children resided at least 100 km away from TUTH. Seventy five (68.1%) patients spent less than a day for hospital visits whereas 35 patients (31.8%) had to spend more than one day for hospital visit. The mean time to reach TUTH was 9.6 hours. Most of the children travelled by bus (72, 65.5%), or by microbus (16, 14.5%) or taxis (10, 9.1%). The average travel cost spent per visit was NRs 1247.79, NRs 2730.50 and NRs 3380 for the distance less than 100 km, 100 km to 299 km and 300 or more respectively. The mean travel cost paid by a caregiver for each hospital visit was NRs 1838.82. Out of 34 patients who stayed with their relatives in Kathmandu, 29 patients had to spend less than NRs 5000 per visit in total costs. Among 22 patients staying at hotel, 17 patients had to spend total costs more than NRs 5000 per visit. Four children used night bus to save lodging cost whereas two children left their native place to stay in Kathmandu for treatment. The total expenditure was less than NRs.1000 for 49 (44.5%) patients whereas 38 (34.5%) patient spent NRs. 1000 to 4999 and 23 (20.9%) patient spent more than NRs 5000 during each hospital visit. The mean expenditure for each hospital visit was NRs. 2942.98. The average time spent during mobile call to caregiver was six minutes and average telephonic cost to investigator in each review was NRs 10.44 per call. Apart from regular scheduled monthly calls, caregivers also sought consultation from the researcher using short messages via mobile, video and audio calls, text based message with different chat platforms such as Whats App, Imo, Viber, for seizure as well as non-seizure medical causes.

Figure 2 below shows numbers and reasons for hospital visits along with hospital admissions of children. 56 (48.69%) did not visited hospital during study period, not even for regular scheduled visit whereas 111 visits were made in hospital by remaining children including those who were lost to follow in telemedicine.

65 (59.1%) had seizure controlled whereas 40(36.4%) had active seizure. Some patients visited hospital (TUTH or other local hospital) for seizure issues other than the scheduled visit.

Five children enrolled in the study died. Of two children who sought hospital admissions in TUTH for seizure, one was mechanically ventilated for status epilepticus and later died due to multiorgan dysfunction because of prolonged hypoxia. The other patient was admitted to titrate up the AED for uncontrolled seizures. From the remaining four children of the five children who couldn't survive, two died due to sepsis in other hospitals and another two children died due to Sudden Unexpected Death in Epilepsy (SUDEP) at home.

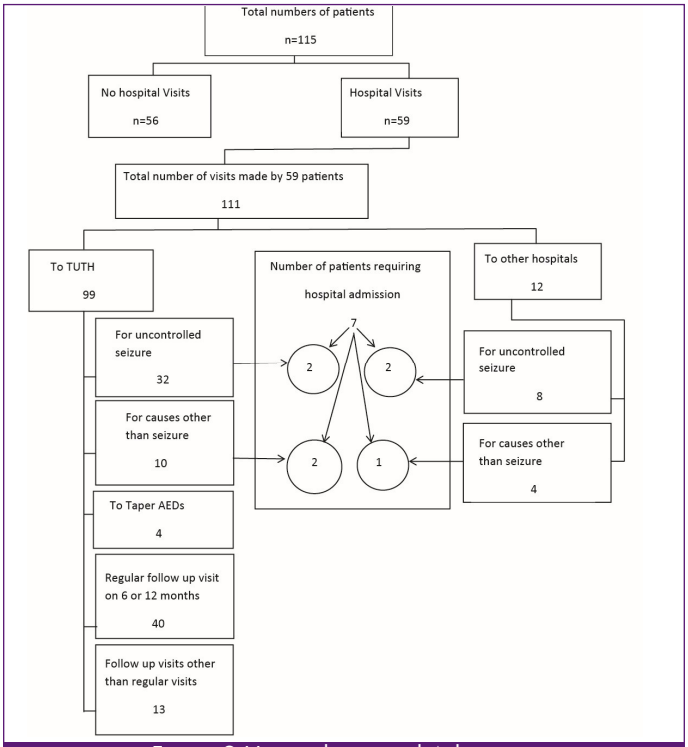

Figure 2 Hospital visit and Admission

The study has been analyzed based on two important aspects, seizure control and satisfaction with telemedicine as a treatment modality.

Seizures were generalized in 66 (60%) patients and focal onset in 40 (36.4%) children. In four (3.6%) patients, caregiver couldn't describe onset of seizure semiology. Out of them, 37 (56%) children of generalized and 26 (65%) of focal onset of seizure had well controlled seizure. Sodium valproate and levetiracetam followed by carbamazepine derivatives were the frequently used AEDs. Ten patients had mild adverse drug reaction (ADR) to AEDs. Comparisons of different factors in children with controlled, uncontrolled seizures and mortality cases are shown in Table 1.

Developmentally normal, greater age at onset of seizure, normal EEG, focal seizure, and seizure being controlled by a single AED seem to be favorable in view of having overall controlled seizure outcome by telemedicine itself. Four children who died during study period had generalized onset of seizure, abnormal EEG, global developmental delay and were on more than one AED.

Factor	Type	Controlled N = 65 (%)	Uncontrolled N = 40 (%)	Mortality N = 5 (%)	Total N =110
Age groups (Years)	1 to 5	14 (45.1)	15 (48.3)	2 (6.4)	31
	6 to 9	20 (55.5)	16 (44.4)	0 (0)	36
	10 to 16	31 (72.0)	9 (20.9)	3 (6.9)	43
Mean age (Years)		9.0	7.0	7.5	
Seizure at onset	Focal	26 (65.0)	14 (35.0)	0 (0)	40
	Generalized	37 (56.0)	25 (37.8)	4 (6.0)	66
	Unknown	2 (50.0)	1 (25.0)	1 (25.0)	4
Seizure etiology	Structural	20 (55.5)	15 (41.6)	1 (2.7)	36
	Metabolic	0 (0)	2 (100.0)	0 (0)	2
	Genetic	13 (65.0)	6 (30.0)	1 (5.0)	20
	Infectious	8 (57.1)	5 (35.7)	1 (7.1)	14
	Unknown	24 (63.1)	12 (31.5)	2 (5.2)	38
Number of AEDs	1	57 (76.0)	17 (22.6)	1 (1.3)	75
	2	6 (31.6)	11 (57.8)	2 (10.5)	19
	More than 2	2 (12.5)	12 (75)	2 (12.5)	16
EEG	Normal	24 (77.4)	7 (22.5)	0 (0)	31
	Abnormal	38 (53.5)	29 (40.8)	4 (5.6)	71
MRI head	Normal	20 (55.5)	15 (41.6)	1 (2.7)	36
	Abnormal	22 (52.3)	18 (42.8)	2 (4.7)	42
CT scan head	Normal	9 (75.0)	3 (25.0)	0 (0)	12
	Abnormal	6 (60.0)	4 (40.0)	0 (0)	10
Developmental delay	Absent	45 (77.5)	12 (20.6)	1 (1.7)	58
	Present	20 (38.4)	28 (53.8)	4 (7.6)	52

At the end of the study, the number of dissatisfied caregivers were three whereas number of caregivers who were neutral to telemedicine as a modality of management were 19. Number of care givers satisfied or strongly satisfied were 83 (75.45%). Satisfaction rate were more for those who needed to spend more time and money for the physical visits irrespective of the seizure control status (Table 2). Average time spend in each call is 6.1 minutes. Eighty eight (80%) caregivers said they would recommend this type of telemedicine to others as well.

Table 2. Comparison of different aspects based on patient and care givers' perception of satisfaction at the end of the (study excluding those who expired N = 105)

Factor	Type	Dissatisfaction (%)	Neutral (%)	Satisfied (%)	Strongly Satisfied (%)	Total N = 105
Seizure control	Controlled	2 (3.07)	11 (16.9)	24 (36.9)	28 (43.0)	65
	Uncontrolled	1 (2.5)	8 (20.0)	18 (45.0)	13 (32.5)	40
Total costs						
per visit (NRs)	Less than 1000	0 (0)	13 (27.6)	17 (36.1)	17 (36.1)	47
	1000 - 4999	2 (5.4)	2 (5.4)	15 (40.5)	18 (48.6)	37
	5000 or more	1 (4.8)	4 (19.0)	10 (47.6)	6 (28.6)	21
Average cost per call (NRs)		11.8	9.94	11.6	9.6	
Total time spent per visit	Less than 1 day	3 (4.3)	15 (20.8)	29 (40.3)	25 (34.7)	72
	1 - 2 day	0 (0)	1 (8.3)	6 (50,0)	5 (41.6)	12
	More than 2 days	0 (0)	3 (14.3)	7 (33.3)	11 (52.3)	21
Distance to TUTH	Less than 100 km	0 (0)	13 (24.5)	23 (43.3)	17 (32.0)	53
	100 - 299 km	2 (5.9)	3 (8.8)	15 (44.1)	14 (41.2)	34
	300 or more km	1 (5.5)	3 (16.7)	4 (22.2)	10 (55.5)	18
Care givers' perception		3 (2.8)	19 (18.0)	42 (40.0)	41 (39.0)	105

The figure 3 below shows different impacts of seizure disorder to children and their caregivers. Some children and caregivers had multiple socioeconomic impacts of seizure.

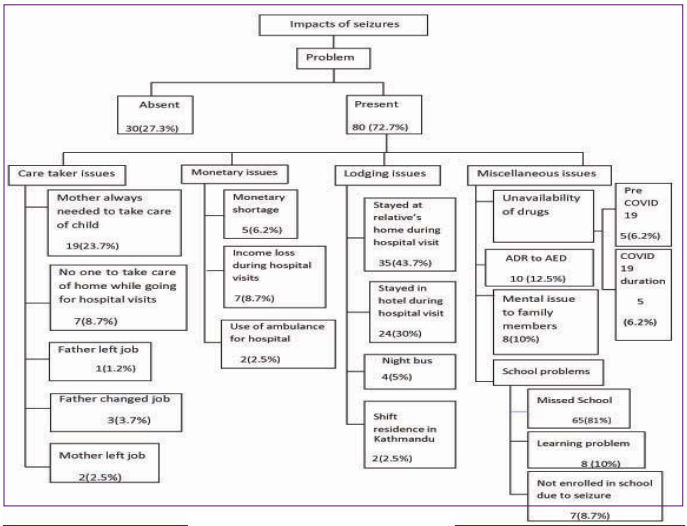

Figure3. Socioeconomic Impact of Seizures

Discussion

The World Health Organization (WHO) has stated telemedicine as a possible information system that can improve the quality and reduce the cost of health care service.[5] Specialized care for patients with epilepsy living in rural areas is also possible via telemedicine.[9] Telemedicine provides patient's as well as health worker's safety especially in situations like the ongoing COVID 19 pandemic with satisfaction for care givers as well.[4,16] In our study, 83 (75.45%) caregivers were satisfied with telemedicine via mobile phones.

Greater age, focal onset of seizure, age appropriate development, normal EEG and seizure being controlled by a single AED were favorable factors in view of having overall controlled seizure outcome by telemedicine. These favorable factors for seizure control are also similar to those factors that confer to low risk of relapse after discontinuation of AEDs in children with partial seizures.[17] Telemedicine for paediatric seizure disorders is very useful optional management modality for a country like Nepal because of its relatively underdeveloped health infrastructure especially in rural areas, lack of adequate specialist health care providers and high costs of travel and time required while seeking treatment. With the advancement in technology and proper upgrading of existing health infrastructure, telemedicine can be a choice of management for most patients with even complicated seizures profile both in diagnostic as well as follow up aspects.

The limitations of our study is that sample size is small and there is no comparison with a control group consisting of an in patient visits. Larger studies can be carried for development of risk stratification score for patient selection as well as to compare the seizure control outcomes between conventional hospital visit group and telemedicine group.

Conclusions

An in-person visit may not be necessary for a child with an established seizure disorder, especially with favorable factors when a caregiver can provide relevant and reliable information, and can follow instructions given by a treating physician via mobile phone. Telemedicine decreases unnecessary high expenses and time to hospital visit when implemented with caution and proper patient selection.

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