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RESEARCH ARTICLE

SOCIO-DEMOGRAPHIC AND CLINICAL PROFILE OF CHILDREN WITH EPILEPSY.

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Abstract

Purpose:- The present study aimed at understanding the socio-demographic and clinical profile of children with epilepsy seeking treatment at a tertiary referral centre for Neurology in South India.

Materials and Methods:- Sixty children in the age-group of 4-15yrswereinterviewedto explore the socio-demographic and clinical profile. The children and their parents were recruited consecutively over a period of six months in 2015. Clinical history was taken from medical records and tools administered were Socio-Demographic Information Schedule and Seizure Severity (SS) scale and a Side-effects (SE) scale- Parent Form[4].

Results:- Most of the children (66.7%) affected with epilepsy were males. Majority of the children (78.8%) had no history of seizures in the family. Maximum number of children (51.7%) had normal birth weight i.e. 2.5 kg and had no congenital anomalies. A significant number of children (58.3%) had generalized tonic clonic seizures. Many children (30.0%) with epilepsy had academic difficulties.

Conclusion:- Children who had unprovoked seizures needs long term follow up studies for better understanding of specific features of epilepsy syndromes as well as for designing better psycho-social treatment plan.

Introduction:-

Epilepsy is a common neurological disorder of childhood which has complex ramifications and epilepsy related seizures can differ widely in terms of severity and in parts of the brain affected. Often, children with epilepsy have other co-existing health conditions that can significantly affect child's health as well as emotional, psychological and social well-being.

Population based studies report a prevalence rate of Epilepsy among children to be 3.6 to 4.2 per 1000 in developed countries[10]and around double these rates in developing countries[21 -6-10].The risk factors included young age of seizure onset, seizure within first few months of birth and family history of epilepsy [17].

A recent study found that in a nationally representative sample from USA, children with seizures were at increased risk for mental health, developmental, and physical co morbidities, increasing needs for care coordination and specialized services [15]. In India, recent studies report a differential distribution of epilepsy among various socio-demographic and economic groups with higher rates reported for the male gender, rural population, and low socioeconomic status[2].

Various studies have explored the link between socio-demographic profile and access to expert health care and antiepileptic drug (AED) prescriptions in children with epilepsy [13] epidemiological perspectives from different parts of the world. Very few studies have explored the clinical and socio-demographic profile of children with epilepsy. It

is envisaged that the understanding gained from the present study will help in developing integrated services for this group.

Objective of the Study:-

Was to understand the socio-demographic and clinical profile of children with epilepsy and to find out the association between socio-demographic factors and seizure severity.

Material and Methods:-

Children diagnosed with Epilepsy in age group 4-15 years, who came for out-patient consultation in neurology department of a tertiary referral centre in South India over a period of six months were included in the study and assessed for socio-demographic and clinical details. Diagnosis of Epilepsy was made on basis of clinical criteria, supported by investigations such as MRI, EEG and biochemistry wherever necessary. Seizure Severity (SS) scale and Side-effects (SE) scale- Parent Form [4] were administered in the interview with child and accompanying parent.

Results:-

Socio-demographic Profile (Table 1):-

The age range of children was 6 to 10 years with a mean age of 8.4years. Majority of children (66.7%) affected with epilepsy were males with only 33.3% females reported being affected with epilepsy in the study group. Most of the children were from urban background (43.3%). Sibling rivalry was not reported among children (71.7%). Significant number of the children (35.0%) were going to a private school but many children i.e. 33.3% has not yet started going to school. When it comes to scholastic performance, many children reportedly performed below average (30.0%) with only 8.3% children performing above average in studies.

Table 1:- Describes Socio- Demographic Profile of Children with Epilepsy.

Variables	Category	Frequency & Percentage
Age	Less than 6 yrs.	14(23.3%)
	Between 6 to 10 yrs.	24(40%)
	Greater than 10 yrs.	22(36.7%)
Gender	Male	40(66.7%)
	Female	20(33.3%)
Domicile	Semi-urban	13(21.7%)
	Rural	21(35.0%)
	Urban	26(43.3%)
Sibling Rivalry	Yes	17(28.3%)
	No	43(71.7%)
Schooling	Not yet started	20(33.3%)
	Govt. School	19(31.7%)
	Pvt. School	21(35.0%)
Standard	Dropout	3(5.0%)
	Class Nursery to Class VIII	37(61.7%)
Scholastic Performance	Below Average	18(30.0%)
	Average	15(25.0%)
	Above Average	5 (8.3%)

Clinical Variables- Birth and Developmental History(Table 2):-

Majority of children had pre-natal complications (56.7%).Most of the children (51.7%) had normal birth weight i.e. more than 2.5kg birth weight and 88.3% had no congenital anomalies(Table 2). Many children had no complications in the first four weeks after birth (53.3%).For 55.0% of children developmental course was normal and they attained their developmental milestones on time. 35%t of children had global developmental delay For those children whose developmental milestone were delayed (36.7%) age at which delay in developmental milestone was first noticed was between 7 to 24 months. Almost 56.7% children needed supervision in activities of daily livings whereas 43.3% children were independent in activities of daily living.

Table 2:- Part I of Clinical Variables: Birth and Developmental History.

Variables	Category	Frequency & Percentage
Pre-natal Complication	Absent Present	26(43.3%) 34(56.7%)
Peri-natal complication	Absent Present	33(55.0%) 27(45.0%)
Birth Weight	Less than 2.5kg Greater than 2.5kg	29(48.3%) 31(51.7%)
Birth Cry	Normal Delayed	35(58.3%) 25(41.7%)
Congenital anomalies	Absent Present	53(88.3%) 7(11.7%)
First four weeks complication	Absent Present	32(53.3%) 28(46.7%)
Child's developmental course	Normal Delayed	33(55.0%) 27(45.0%)
Domains delayed	No delay Specific domains All the domains	33(55.0%) 6(10.0%) 21(35.0%)
Age delay first noticed	Less than 6 months Between 7 to 24 months Greater than 24 months No delay	4(6.7%) 22(36.7%) 4(6.7%) 30(50%)
ADLs(Activities of Daily Living)	Independent Needs supervision	34(43.3%) 26(56.7%)

Clinical Variables- Seizure Details of Children (Table 3):-

Majority of children (78.3%) had no history of seizures in the family. In study group, 58.3% of children were case of chronic seizures where as 41.7% reported new-onset seizures. Majority of the children who had long term seizures have had them since birth. Among the children with recent onset seizures, youngest age of onset was four years. Findings also shows that average number of children (50%) had generalized seizures with only 31.7% of children having partial seizures. Small percentage had a combination of both Generalized and partial seizures (18%). Most of the children had seizures lasting less than 5 seconds (63.3%).Majority of children's (73.3%) seizure has not been controlled with single anti-epileptic drug treatment. Many children had history of being hospitalized for seizures at least once (53%). In terms of co-morbid conditions 26.7% of children had Cerebral Palsy followed by 16.7% having mental retardation. Around 3% of children had co-morbid diagnosis of autism and attention deficit hyperactivity disorder.

Table 3:- Part II of Clinical Variables: Depicts Seizure Details of Children.

Variables	Category	Frequency & Percentage
Family Seizure History	Absent Present	47(78.8%) 13(21.9%)
Diagnosis of Seizure Disorder	Chronic New onset	35(58.3%) 25(41.7%)
Seizure onset age (Months)	Less than 6 months Between 6 to 24 months Greater than 24 months	10(16.7%) 7(11.7%) 43(71.7%)
Main seizure type	Generalized seizures Partial Seizures Combination of both Generalized and partial	30(50.0%) 19(31.7%) 11(18.3%)
Duration of seizure	Less than 5 sec. Between 5 to 10 sec. Greater than 10 sec.	38(63.3%) 17(28.3%) 5(8.3%)
Frequency of episodes	Less than 10 times a day Between 10-20 times a day More than 20 times a day	27(45.0%) 15(25.0%) 18(30.0%)
Seizure control	Not control Control	44(73.3%) 16(26.7%)
Hospitalization	Yes No	32(53.3%) 28(46.7%)
Co-morbid condition	No co-morbidity Cerebral Palsy Mental Retardation Autism Attention Deficit Hyperactivity Disorder(ADHD)	30(50.0%) 16(26.7%) 10(16.7%) 2(3.3%) 2(3.3%)

Seizure Severity (SS) Scale score (Table 4):-

Seizures were characterized by loss of consciousness among 32% of children with postictal confusion. Seizures were associated with urinary incontinence (30%), and motor symptoms like eye blinking, lip smacking, unusual sounds or trouble talking during seizures(28%). Postictal phenomena reported were unusual drowsiness, sleep and headache or muscle pain/lethargy (16 – 25%). Overall severity of seizure was mild to moderate for majority of the children (58.3%).

Table 4:- Seizure Severity (SS).

Symptoms during and after Seizures	Frequency & Percentage
Decrease in Consciousness	19(31.7%)
Confusion during seizures	16(26.7%)
Urine Incontinence	18(30%)
Motor Symptoms-eye blinking, lip smacking, unusual sounds or trouble talking	17(28.3%)
Jerky Movements	9(15%)
Postictal Sleep	10(16.7%)
Postictal Headache or Muscle Pain	15(25%)
Decrease of consciousness short period of time	37(61.7%)
Short period of time duration of jerks	29(48.3%)
Short period of time taken to resume normal activity	32(53.35%)
Mild to Moderate Severity of Seizures	35(58.3%)
Seizure fairly noticeable	30(50%)

Side-Effects of antiepileptic medications(Table 5):-
Common side effect reported was dizziness (82%), loss of appetite (76.7%) as well as bowel disturbances (63.3%).Significant number of children reported fatigability or tiredness as one of the side-effects of anti-epileptic medication. Relatively fewer number of children reported sad mood (28.3%), headache (25%), speech difficulties (21.7%), shaking (20%), blurred vision(16.7%) and uncertainty when walking (10%) as some other toxic side-effects of anti-epileptic drugs.

In terms of chronic side-effects of anti-epileptic medication majority of children (75%) had behavioral disturbances and temper tantrums (70%). Significant number of children had difficulty in concentration (68.3%) and restlessness (63.3%) which led to poor scholastic performance(43%).

Table 5:- Depicts Side-Effects (SE) Scale Score.

Toxic Side Effects	**Frequency & Percentage**
Drowsiness	32(53.3%)
Dizziness	49(81.7%)
Uncertainty when walking	6(10%)
Difficulty with Defecation	38(63.3%)
Shaking	12(20%)
Speech Difficulties	13(21.7)
Blurred Vision	10(16.7%)
Headache	15(25%)
Fatigue	36(60%)
Loss of appetite	46(76.7%)
Sad Mood	17(28.3%)
Chronic Side Effects	**Frequency & Percentage**
Restlessness	38(63.3%)
Temper Tantrums/Aggression	42(70%)
Slowness	16(26.7%)
Poor Scholastic Performance	26(43.3%)
Decreased Concentration	41(68.3%)
Behavioural Disturbances	45(75%)

Association between Seizure Severity & socio-demographic factors(Table 6):-
There was strong positive correlation between presence of congenital anomalies and seizure severity ($\rho < 0.01$). There was strong positive correlation between seizure severity and birth cry ($\rho < 0.01$), delay in developmental course of the child($\rho < 0.01$and presence of co-morbid conditions($\rho < 0.01$). There was strong negative correlation between seizure severity and activities of daily living($\rho < 0.01$).
Table 6:- Shows Co-relates of Seizure Severity.

Variable	**Co-related variable**	**Spearman's rho**	
		Correlation Coefficient	**P value**
Seizure Severity	Congenital Anomalies	.349**	.006
Seizure Severity	Birth Cry	.355**	.005
Seizure Severity	Delayed in developmental Course	.389**	.002
Seizure Severity	Domains of milestone delayed	.384**	.002
Seizure Severity	Co-morbid Conditions	.446**	.000
Seizure Severity	Activities of Daily Living	-.407**	.001
(**) Correlation is significant at the 0.01 level (2-tailed).			

Discussion:-

In this study, most of the children diagnosed with seizure disorder were males and aged between 6 to 10 years and only 28.3% children with epilepsy reported having sibling rivalry which was contrary to the findings of many studies[11 - 1]. All these studies has reported that in a serious sickness period healthy siblings are unhappiest and most emotionally ignored individuals of a family. Siblings of children with chronic illness like epilepsy also have increased behavioral problems and emotional problems.

Another interesting finding was majority of children has not yet started going to school. Mostly those children were who had neonatal seizures as a result had delay in developmental milestones. Other reason was when seizures persisted beyond a certain age it affected child's growth and development and overall functionality. Parents had not sent their children with epilepsy to school fearing child will have an episode of seizures at school and also there was some concerns related to school authority and children would come to know about child's illness and treat him/her differently. In the current study there were many children who were going to school had academic difficulties as a result poor scholastic performance. Most of these children were having difficulty to concentrate for a longer period of time or difficulty in comprehending the subject because of having seizures for so many years. Soria and colleague[20]in their study has found that children with epilepsy has associated problems like learning difficulties or cognitive impairment, difficulty to concentrate along with behavioral problems.

Maximum number of children in present study had found to have normal birth weight (51.7%) with no congenital anomalies (88.3%). In one of the study done by Holden and colleague[10]reported that congenital anomalies were a major indicator of seizures in children and predictor of subsequent neurologic deficit but most infants with neonatal seizures do not have congenital anomalies.

The current study also revealed that average number of children had normal birth weight (51.7%) but had pre-natal(56.7%) and peri-natal(45.0%) complications like low birth weight, maternal hemorrhage, assisted vaginal delivery, post-term birth and not breastfeeding their infant. Similar findings were reported by Gretherand colleague [7] in their study that maternal infection increases the risk of neonatal seizures of even normal birth weight child.

Many children (46.7%) in the present study had first four weeks complications like respiratory distress, jaundice, high grade fever, hypoglycaemia and has received incubator care. These children had developed all those problems because of pre-natal and peri-natal complications like mother having infection during pregnancy, pre or post-term delivery. Mostly those children where the ones who later on developed co-morbid conditions like cerebral palsy or mental retardation.

Majority of children in this study needed supervision and assistance in activities of daily living like feeding, bathing, taking medicines, communication and mobility. The level of independence for activities of daily living in children depended upon parents judgment whether the child was capable of living independently and confidence of parents in the epileptic child's ability to manage their day to day life which was corroborated by the findings of the study done by Camfield & Camfield[3].

The present study also showed that children who had history of seizures in their family were having history in first degree relatives mostly child's mother. This may be because of genetic transformation (vulnerability) which may be associated with seizure history in the first degree relative especially in mother and risk of offspring vulnerability might increase in such conditions. Present findings were consistent with previous findings of the study done by Ottman, Annegers & Titzet[14 -22].

In the current study generalized seizures like absence seizures, myoclonic jerks or tonic-clonic seizures were more prevalent in average number of children of age- group 6yrs.-15yrs. and partial/ localization-related in (31.7%) children of age-group 0-6 yrs. Absence seizures were non-convulsive, i.e., they do not spread to the other part of the brain as a result it was quiet difficult for the parents to identify it as seizures as child seem briefly inattentive or appear to be daydreaming and no motor symptoms were there which was easily visible and identifiable. Similar findings were reported by the study done by Eriksson &Koivikko[6].

This study also highlighted that seizures when poorly controlled, may be disabling and interfere with the child's ability to learn and hinders their normal growth and development, whereas secondary factors, such as stigma and lack of knowledge about the epilepsy can negatively affect social and psychological functioning of the child which was consistent by the findings of the study done by Wu & Russ[18 - 15].

One of the interesting findings of the present study was most of the children with cerebral palsy had intellectual developmental delay which was consistent with the findings of the study done by Singhi [19]. Another important finding of this study was children with epilepsy and intellectual developmental delay were having more behavioral disturbances like difficulty in regulating their anger, stubbornness and temper tantrums.

In the current study seizure severity was assessed using the parent-completed scales for measuring seizure severity by Carpay [4]. Only (28.3%) children had Motor Symptoms-eye blinking, lip smacking, unusual sounds or trouble talking. Hauser[8]in their study has reported that not all the children with seizures had motor symptoms but has some confusion, decrease of consciousness and after effects of seizures like headache, muscle pain or sleep etc. which was consistent with our findings. Nelson and colleague [12] reported in their study that most of the children had motor seizures and average number of children who had motor symptoms had congenital anomalies which were contrary to our findings.

Majority of children had cognitive side-effects of anti-epileptic drugs which were chronic in nature and difficult to control which was mostly due to the recurrent seizures, side-effects of medication and parents being too indulgent or restrictive with the child. Similar findings were reported by Hermann [22]

Sahar [16] has reported that it was important to understand the association between various clinical features of epilepsy which determine the severity of seizures and helps clinician to assess the psychological, social and behavioral aspects of epilepsy. Accordingly, improvement can be made in the management plan keeping in consideration all those clinical factors.

Some of the limitation of this study was only those children were included who came on out-patient basis for treatment. Another limitation was only parents were interviewed not children who would give better account of their experience during and after seizures.

Conclusion:-

Children who had unprovoked seizures needs long term follow up studies for better understanding of specific features of epilepsy syndromes as well as for designing better psycho-social treatment plan which would take into consideration psychological, social and behavioral aspects of epilepsy as well.

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References:-

1. C. B. Baca, B. G. Vickrey, R. D. Hays, S. D. Vassar and A. T. Berg, "Differences in child versus parent reports of the child's & health-related quality of life in children with epilepsy and healthy," Value in Health, vol. 13, no. 6, pp. 778-786; 1524-4733, 2010.
2. Senthil, G. Gopalkrishna and S. Parthasarathy, "Epilepsy in India II: Impact, burden, and need for a multisectoral public health response," Annals of Indian Academy of Neurology, vol. 18, no. 4, p. 369, 2015.
3. Camfield and P. Camfield, "Twenty years after childhood-onset symptomatic generalized epilepsy the social outcome is usually dependency or death: a population-based study," Developmental Medicine & Child Neurology, vol. 50, no. 11, pp. 859-863; 1469-8749, 2008.
4. H. A. Carpay, W. F. Arts, J. Vermeulen, H. Stroink, O. F. Brouwer, A. B. Peters, C. A. van Donselaar and A. P. Aldenkamp, "Parent-completed scales for measuring seizure severity and severity of side-effects of antiepileptic drugs in childhood epilepsy: development and psychometric analysis," Epilepsy research, vol. 24, no. 3, pp. 173-181; 920-1211, 1996.
5. D. MB, "Epilepsy in rural Ugandan children: seizure pattern, age of onset and associated findings," African health sciences, vol. 10, no. 3, pp. 1680-6905, 2010.

6. E. KJ and K. MJ, "Prevalence, classification, and severity of epilepsy and epileptic syndromes in children," Epilepsia, vol. 38, no. 12, pp. 1275-1282, 1997.
7. J. K. Grether and K. B. Nelson, "Maternal infection and cerebral palsy in infants of normal birth weight," Jama, vol. 278, no. 3, pp. 207-211, 1997.
8. A. W. Hauser, "The prevalence and incidence of convulsive disorders in children," Epilepsia, vol. 35, no. S2, pp. 1528-1167, 1994.
9. C. Hocaoglu and A. Koroglu, Childhood age epilepsy and family, INTECH Open Access Publisher, 2011.
10. K. R. Holden, D. E. Mellits and J. M. Freeman, "Neonatal seizures I. Correlation of prenatal and perinatal events with outcomes," Pediatrics, vol. 70, no. 2, pp. 165-176, 1982.
11. J. Mims, "Self-esteem, behavior, and concerns surrounding epilepsy in siblings of children with epilepsy," Journal of child neurology, vol. 12, no. 3, pp. 187-192, 1997.
12. K. B. Nelson and J. H. Ellenberg, "Antecedents of seizure disorders in early childhood," American journal of diseases of children, vol. 140, no. 10, pp. 1053-1061, 1986.
13. N. RA, S. MM, M. RH and C. JA, "Behavioral toxicity associated with antiepileptic drugs: Concepts and methods of assessment," Epilepsia, vol. 27, no. 4, pp. 331-340; 1528-1167, 1986.
14. O. R, A. JF, H. WA and K. LT, "Higher risk of seizures in offspring of mothers than of fathers with epilepsy.," American journal of human genetics, vol. 43, no. 3, p. 257, 1988.
15. S. A. Russ, K. Larson and N. Halfon, "A national profile of childhood epilepsy and seizure disorder," Pediatrics, vol. 129, no. 2, pp. 256-264, 2012.
16. N.-u. Sahar, "Assessment of psychological distress in epilepsy: Perspective from Pakistan," Epilepsy research and treatment, vol. 2012, no. 1, pp. 1348-2090, 2012.
17. V. Udani, "Pediatric epilepsy—an Indian perspective," The Indian Journal of Pediatrics, vol. 72, no. 4, pp. 309-313, 2005.
18. K. N. Wu, E. Lieber, P. Siddarth, K. Smith, R. Sankar and R. Caplan, "Dealing with epilepsy: Parents speak up," Epilepsy & Behavior, vol. 13, no. 1, pp. 131-138, 2008.
19. P. Singhi, S. Jagirdar, N. Khandelwal and P. Malhi, "Epilepsy in children with cerebral palsy," Journal of Child Neurology, vol. 18, no. 3, pp. 174-179, 2003.
20. C. Soria, S. Escolano, S. El Sabbagh, S. Chmura, C. Bulteau, C. Chiron and G. Dellatolas, "Behavioral problems, cognitive difficulties and quality of life in children with epilepsy: An analysis of parental concerns," Child Neuropsychology, vol. 18, no. 3, pp. 209-227, 2012.
21. C. AL, Z. ME, M. P, R. E, V. A and K. JG, "Epilepsy in rural South African children--prevalence, associated disability and management.," South African medical journal= Suid-Afrikaanse tydskrif vir geneeskunde, vol. 90, no. 3, pp. 262-266, 2000.
22. K. Titzet, S. Koch, H. Helge, U. Lehmkuhl, H. Rauh and H. Steinhausen, "Prenatal and family risks of children born to mothers with epilepsy: effects on cognitive development," Developmental Medicine & Child Neurology, vol. 50, no. 2, pp. 117-122, 2008.