Research Paper

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Quality of Life Among Paediatric Epileptic Patients in Rural Area of Tamilnadu – A Hospital Based Study

Medical Science

KEYWORDS : Children, Epilepsy, Quality of life.

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ABSTRACT

Background: Epilepsy is a common chronic neurological illness in children with prevalance being 3.6- 44/1000 in underdeveloped countries. The burden of the disease is enormous and there is a dearth of information on the morbidity and social impact of epilepsy on the children. Managing a child with epilepsy has important implications on the total well being of the family. Hence analyzing the children with seizures to know the psychosocial impact of it on the child and its family can be a useful epidemiological tool to assess the Quality of life among epileptic children in the family.

Methodology:

The study was conducted in Neurology Department of Government Tirunelveli Medical College for a period of 2 months from January 2015-February 2015. 100 epileptic children who attended the neurology OPD were selected randomly. After obtaining verbal consent from the mothers semi-structured questionnaire was administered and data regarding the type of seizure disorder, duration of treatment, relationship of the child with the parents, peergroup,siblings and neighbours and any other physical and mental limitations were obtained.

Results:Out of the 100children,75 children had epilepsy alone and 25 children had epilepsy and mental retardation. 26 are not going to school due to developmental delay and repeated seizure attacks.56 children are going to regular school and 6 are going to special school. Epileptic children with mental retardation (25) are having low quality of life as compared to children with epilepsy alone (75). The study reveals that frequent seizure attacks affects the quality of life of the children and the entire family. Epilepsy had an impact on cognition, memory and social interaction of the child suggesting the need for rehabilitation among them.

Introduction:

Epilepsy is a common, chronic neurological problem affecting many children in our country. The management of epilepsy requires recognition of potential effect of epilepsy on all aspects of life. It is increasingly being recognized that health related quality of life measurement adds new and important information to other traditional health outcome measures such as seizure control and cognitive improvement. Quality of life is the subjective feeling of well being and it predicts the subjective feeling of happiness or unhappiness about various life concerns. Assessing the quality of life can also reflect the overall mental well being. Pediatric epilepsy being an important determinant of child's intellectual development is taken for this study and social impact of it on the child is assessed.

Methodology:

Study design:

Hospital based Cross-Sectional Study

Study period:

2 months from January 2015 –February 2015.

Study population:

100 epileptic children of less than 12 yrs who attended the Neurology Outpatient Department were selected randomly and those who were willing were included for the study. Informed consent was obtained from the mothers of these epileptic children.

Data collection:

The Mothers were interviewed using a semi-structured questionnaire. Questions were asked regarding age of the child, sex, place of residence, family type, educational status of the parents, total income of the family, type of epilepsy, mental development of the child and school performance. Questions were also asked regarding the relationship of the child with the parents, siblings, peergroups and neighbours and vice versa.

The"Impact of Pediatric epilepsy scales (IPES)was used to assess the Quality of Life among these children.Scores were given to each answer to determine the negative impact of epilepsy on the children.

Scores were as follows:

1-Affected a lot
2-Some
3-Affected a little
4-Not at all affected.

Based on this a maximum score of 32 was given to each child to know the effect of epilepsy on the quality of life of the child. Score less than 26 indicated poor quality of life.

Ethical approval was granted by Institutional Ethical Committee to conduct the project in the hospital

Data analysis was done using SPSS.

Results:

Out of the 100 Children attending the pediatric seizure OPD, 66 were male and 34 were female. Among the male children, 74.2% were normal and 25.8% were mentally retarded. Among the female children, 76.5% were normal and 23.6% were mentally retarded.

In these 100 children,26 were not going to school due to developmental delay and repeated seizure attacks.56 children were going to regular school and 6 were going to special school. All children were taken care by their mothers. 29 of the mothers were illiterate and 71 were literate. 24 of the mothers were working.

None of the mothers had any antenatal complications. About birth history, 14 were preterm children out of which 43% were mentally retarded.

These children were categorized based on three types of seizures: Generalized (26%), partial (52%) and unclassified (neonatal and febrile) (22%) .18 children had a family history of seizure.18 children were observed to have experienced aura before the seizure attack.

At present all 100 children strictly adhered to the treatment regimen. 20% mothers have stopped the drug regimen atleast once. They restarted the regimen on recurrence of the seizures.

74 children are under treatment for more than one year. 43

mothers reported that there was difficulty in managing the child, mainly in financial aspects. 22 mothers were not receiving any support from their family members.

By parent's score to the children, it was found that 49 children scored below 26. Children of illiterate mothers scored lesser. Maternal education, type of epilepsy and age group of the children influence this score. Epilepsy had an impact on cognition, memory and social interaction of the child. Children with partial epilepsy (about 50%) scored lesser when compared with other two types.

Discussion:

Standard measures to assess health related quality of life in children with epilepsy are lacking in India. Also, that epilepsy has an impact on memory, speech, physical restrictions,

Age of the epileptic children was seen to affect overall quality of life. In 10-12 years age group, out of 37 who were interviewed, 22 children scored lesser.

50% children of illiterate mothers scored lesser. There was no significant difference between genders. Overall quality of life was significantly more compromised in patients with partial epilepsy, compared to generalized epilepsy.

Conclusion:

Measure to improve the quality of life of epileptic children should be a part of the treatment protocol of epilepsy. The quality of life in families could be profoundly affected, when a child has epilepsy. The quality of life of the entire families appears to vary according to both seizure frequency and severity. Rehabilitation services and counselling services would be of paramount importance in improving the Quality of life these type of chronic illnesses.

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FIG 1: DISTRIBUTION OF CHILDREN BASED ON MENTAL DEVELOPMENT:

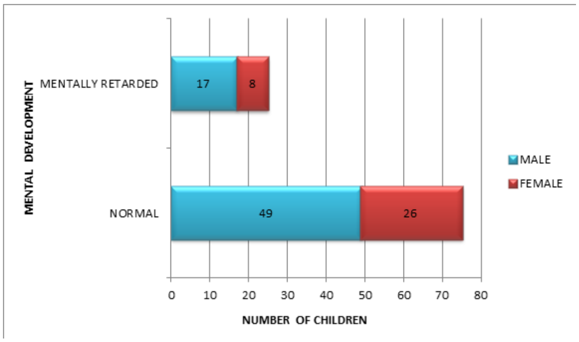

FIG 2: DISTRIBUTION OF CHILDREN BASED ON AGE:

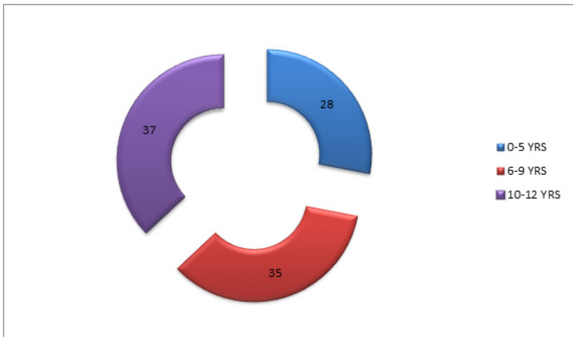

FIG 3: DISTRIBUTION OF CHILDREN BASED ON THE TYPE OF SEIZURE:

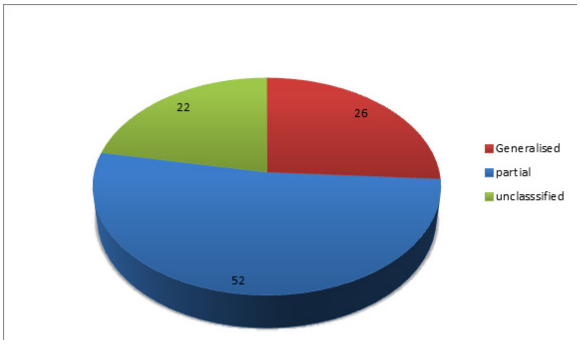

FIG 4: DISTRIBUTION OF CHILDREN BASED ON SCHOOL PERFORMANCE:

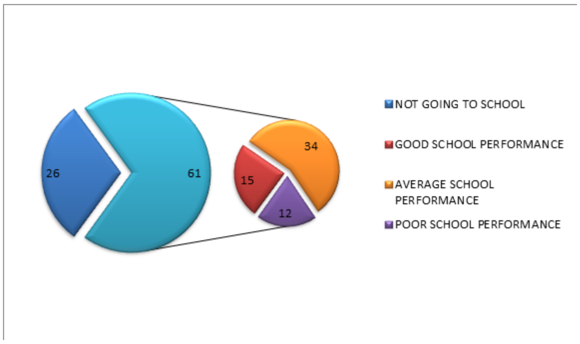

TABLE 1: Distribution of children based on duration of illness:

Age group of the children	**< 1 month**	**months**	**6 month-1 yr**	**>1 year**	**Total**
< 1 year	-	1	1	-	2
1-5 year	-	4	5	19	28
5-10 year	-	4	5	36	45
>10 year	1	1	14	19	35
Total	1	10	15	74	100

TABLE 2: QUALITY OF LIFE WITH RELATIONS

CHILD'S RELATIONSHIP WITH	**A LOT (1)**	**SOME (2)**	**A LITTLE (3)**	**NOT AT ALL (4)**	**TOTAL**
Parents	-	5	28	67	100
Siblings	2	10	36	52	100
Peer group	5	11	44	40	100
Neighbour	18	13	36	43	100

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