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Original Article

COMPARISON OF QUALITY OF LIFE OF CHILDREN WITH EPILEPSY AND NORMAL CHILDREN

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ABSTRACT

Introduction : Epilepsy is the second most common and frequently encountered neurological condition that enforce heavy burden on families, and on healthcare system. Almost 1% of all children have epilepsy with highest incidence in the preschool years (3-6 years).[1] The objectives of study were to assess and compare the quality of life of children with epilepsy and normal children; to find out the association between the quality of life of children with epilepsy and selected variables.

Methods : Quantitative research approach was used to compare the quality of life of children with epilepsy and normal children. The sample comprised of 30 Children with epilepsy and their parent from pediatric OPD of UPUMS Saifai and 30 Normal children and their parent from Niloi, Jaswant Nagar, and Etawah were selected purposively. The data was collected by PedsQL version 4 inventory. The final study was conducted in the month of December 2016 and January 2017.

Result : Findings of the study showed the overall mean score of quality of life of normal children was higher than the overall mean score of children with epilepsy. The computed t-value was found to be statistically significant at 0.05 level of significance shows that the normal children had the better quality of life than the children with epilepsy. Study further showed that there was no significant difference found between mean score of Children with epilepsy and normal children as assessed by child report or parent report of Peds QL version 4 inventory.

Conclusion : Normal children had better quality of life than children with epilepsy and the quality of life of normal children and epilepsy children can be assessed by either of child report or parent report of Peds QL version 4 inventory A study can be replicated on a larger sample of children with epilepsy and normal children with their parents from areas of Uttar Pradesh for wider generalization of the findings.

Keywords : Epilepsy , quality of life , children with epilepsy, normal children.

INTRODUCTION :

Childhood epilepsy is one of the most prevalent neurological conditions. Children with epilepsy are at a high risk for poor psychosocial outcomes, even without experiencing co-morbidity. [2] The cause of epilepsy in children can be genetic, developmental or related to an abnormality acquired early in life in association with learning difficulties and impairments.[3]

Epilepsy is characterized by its episodic and chronic nature. The seizures usually produce brief periods of disruption, which may include loss of consciousness , bodily distortion, injuries unusual and often frightening psychological experiences as well as urinary and bowel incontinence. The unpredictability of seizure recurrence is a constant threat to the child with epilepsy and his or her family. Apart from the episodic seizures, there are many other factors i.e. social, psychological, behavioral, educational and cultural also affect the lives of children with epilepsy, and their families. These factors vary individually, but have a significant impact on the quality of life in every affected child.[4]

Epidemiological studies in India on epilepsy are comparable to the developed countries, with a prevalence rate of 5 per 1000 and incidence rate of 50 per 100, 000.[5] Co-morbidities, rather than seizure variables, are related to the poor health-related quality of life (HRQOL) found in pediatric epilepsy. However, child HRQOL studies in which cognition-rather than behavioral problems or psychiatric co-morbidities-was a significant predictor often included children with developmental disabilities, low IQ scores, neurological handicaps, and easily onset intractable seizures of note , children with developmental disabilities without epilepsy also have poor HRQOL.[6]

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It is extremely difficult for parents to fully admit and accept that their children are diagnosed as having epilepsy. They are overwhelmed by enormous worries and concerned about the child's prognosis, unpredictable nature of epilepsy, the side effect of anti - convulsions and the impairment to the brain function as well as their future career and marriage.[7]

Epilepsy is not only a medical and personal condition, but also a social and public health issue which requires multi-disciplinary and multi -level intervention. Together with the individual treatment by medical professionals, self- management, self-help and social awareness among the children,parents and the public will also be critical to enhance the quality of lives of patients and to promote a more inclusive society.[8]

In response to the needs of patients with epilepsy and their family members, community rehabilitation network,(CRN) started epilepsy services in 1994 . It has been under the subvention of the social welfare department since 1997. Three intervention strategies are effective in helping the patients in the community, namely self -management mutual support and social awareness. Community education programmes include school education, awareness campaign, day care, and production of educational materials like the 'Demystifying epilepsy'education kit. A more informed public and positive attitude will also help the under - diagnosed patients to seek treatment.[9]

NEED OF THE STUDY

Childhood Epilepsy is the most prevalent and important neurological conditions in the developing years. Population based studies report the prevalence rates of 3.6-4.2 per 1000 children in developed countries, and approximately double these rates in developing countries.

The unique feature of epilepsy among other chronic conditions is its direct effect on the brain. This might contributes to more disturbed psychosocial functioning in patients diagnosed with epilepsy as hypothesized that foci lateralization correlates with a reduced QOL in children with unilateral epilepsy thus confirming a direct brain-behavior intersection influencing QOL during development.[10]

Bishop and Allen (2003) reported that epilepsy had both direct and an indirect impact on quality of life among adults.[11] High prevalence of depression was found in children and adolescents with epilepsy. It also shows that epilepsy has a negative impact on their quality of life. Therefore, there is a need to pay more attention to epileptic children, in order to reduce the frequency of seizures and improve their psycho-social well-being.[12]

One Dutch study underwent a detailed examination of, when educational and psychosocial deprivation begins in children newly diagnosed with epilepsy. It found that early on, children need special assistance at school. However, the cognitive and behavioral difficult experience were not only due to the epilepsy rather other contextual factors affected this, major factors i.e. the negative emotions and anxious reaction of parents to their child's epilepsy can affect their academic skills , learning and attention and how they adopt to their condition (Oostrom , smeets - schouten et al .2003). As children spend a significant amount of time in the classrooms, schools are among the most effective contexts for promoting the psychological, social and physical health of school-age children . Despite this opportunity there is a lack of QOL research that specifically focuses on the school experiences of children with epilepsy which can help educators understand how to best support, accommodate, and prepare these children in their classes.xvi Researcher felt need to compare the quality of life of children with epilepsy and normal children in selected area of Saifai, Etawah.

STATEMENT OF THE PROBLEM

"A comparative study to assess the quality of life of children with Epilepsy and Normal children in a selected area of Saifai, Etawah"

OBJECTIVE OF THE STUDY

1. To assess & compare the quality of life of children with epilepsy and normal children.
2. To find out the association between the quality of life of children with epilepsy and selected variables.

HYPOTHESES

The following hypotheses will be tested at 0.05 level of Significance:

H1 : There will be a significant difference in the quality of life of children with epilepsy and normal children.

H2 : There will be a significant difference in the quality of life of children with epilepsy and normal children assessed by child report and parent report of Peds QL version 4 inventory.

DELIMITATION

The study delimited to:

1. Children with epilepsy (5-18 years) and their parent coming to pediatric OPD of UPUMS, Saifai.
2. Normal children and their parent living in Jaswant Nagar.

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METHODOLOGY :

A quantitative research approach was used to achieve the objectives of the study. A comparative research design considers to be the most appropriate. The setting selected for the present study were the pediatric OPD of UPUMS Hospital, Saifai for the epilepsy children and selected area of Jaswant Nagar for the normal children. Purposive sampling technique was used to select 30 Children with epilepsy and their parent attending the pediatric OPD of UPUMS Hospital, Saifai ,Etawah and 30 normal children and their parents from the selected area of Jaswant Nagar, Etawah. Parents and their Children between the age group of 5-18 years and are taking treatment at least for last 6 months were selected. Children having other chronic illness were excluded.The Standardized pediatric quality of life inventory (Peds QL) version 4 were used to assess the quality of life of children. The Peds QL version 4 scales are multidimensional child Self-report and parent proxy-report scales developed as the generic core measure to be integrated with the Peds QL Disease-Specific Modules. The Peds QL version 4 scales consist of 23 items applicable for healthy school and community populations, as well as pediatric population with acute and chronic health conditions. Quality of life questionnaire includes parallel child self-reports (5-7 yrs, 8-12 yrs and 13-18 yrs). Item responses are measured on a five-point rating scale ranging from 0 (Never a problem) to 4 (almost always a problem). The 23 items consist of 8 items on physical function, 5 items on emotional function, 5 items on social function and 5 items on school function. As per the scoring system of Peds QL, items are reversed scored and linearly transformed to a 0-100 scale as per follows: 0=100, 1=75, 2=50, 3=25, 4=0 and if more than 50% of the items in the scale are missing, the scale scores should not be computed. Internal consistency reliability ((?) for the total scale score of Peds QL version 4 for children report was 0.88 and parents report was 0.90 respectively. Internal consistency reliability (?) for Physical health summary score of psychosocial health summary score were (alpha=0.80 for child, 0.08 for parents) and (alpha=0.83 for child, 0.86 for parents) were acceptable for group comparisons. Ethical approval was taken from the Institutional ethical committee for conducting the study.

DATA ANALYSIS AND INTERPRETATION:

Table-1: Mean, SD and t value between quality of life scores of epilepsy children and normal children as reported by children

N=60

	Mean	SD	t value
Epilepsy Children	1537.50	518.56	4.95*
Normal Children	2033.34	176.45	

t (59)=2.00 <0.05 level of significance

The data presented in table 1 showed that the overall mean quality of life score of normal children (2033.34+ 176.45) was higher than the overall mean score of children with epilepsy (1537.50+ 518.56). The computed t-value of 4.95 was found to be statistically significant at 0.05 level of significance which shows that the mean difference between mean score of Children with epilepsy and Normal children was a true difference and not by chance. Hence it can be concluded that the normal children had the better quality of life than the children with epilepsy as reported by the children.

Table-2: Mean SD and t value between quality of life scores of epilepsy children and normal children as reported by parents:

N=60

Domain	Mean	SD	t value
Epilepsy Children	1643.34	432.86	2.59*
Normal Children	2074.16	156.81	

t (59)=2.00 <0.05 level of significance

The data presented in table 2 showed that the overall mean score of quality of life of normal children (2074.16+156.81) was higher than the overall mean score of children with epilepsy (1643.34+432.86). The computed t-value of 2.59 was found to be statistically significant at 0.05 level of significance which shows that the mean difference between mean score of Children with epilepsy and normal children was a true difference and not by chance. Hence it can be concluded that the normal children had the better quality of life than the children with epilepsy as reported by the parent.

Table- 3: Mean, SD and t value calculated in quality of life score of normal children as reported by children and parent:

N=60

Domain	Mean	SD	t value
Normal children	2033.34	176.45	0.94NS
Parent of Normal children	2074.17	156.81	

t (59)=2.00 <0.05 level of significance, NS- Non-Significant

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The data presented in Table 3 showed that the overall mean score of quality of life of normal children as reported by parent (2074.17+156.81) was higher than the overall mean score of normal children reported by children (2033.34+176.45). The computed t-value of 0.94 was not found to be statistically significant at 0.05 level of significance which shows that there was no significant difference between mean score of Children with epilepsy and normal children. This difference may be by chance. Hence it can be concluded that quality of life of normal children can be assessed by either of child report or parent report of Peds QL version 4 inventory.

Table-4: Mean, SD and t value calculated in quality of life score of epilepsy children as reported by children and parents:

N=60

Domain	Mean	SD	t value
Epilepsy Children	1537.5	518.56	0.85
Parent of Epilepsy children	1643.34	432.86	

t (59)=2.00 <0.05 level of significance, NS-Non-Significant

The data presented in table 4 showed that the overall mean score of quality of life of children with epilepsy as reported by parent (1643.34+432.86) was higher than the overall mean score of children with epilepsy as reported by children (1537.5+518.56). The computed t-value of 0.85 was not found to be statistically significant at 0.05 level of significance which shows that the mean difference between mean score of children with epilepsy and normal children may be by chance. Hence it can be concluded that quality of life of children with epilepsy can be assessed by either of child report or parent report of Peds QL version 4 inventory.

DISCUSSION

The present study findings indicated significant difference between the quality of life of children with epilepsy and normal children. These findings were consistent with the findings of Bansal Dipika 2015 who reported that children with epilepsy had diminished score in total score and all sub domains of PedsQL. In contrary the findings are not supported by Josi Poonam et al (2003) which showed that children with epilepsy perceived better health related quality of life than the normal children overall. The present study indicated that there was no significant association found between the quality of life of epilepsy children and the education of mother. In contrary Nagesh Adla et al (2017) reported that Quality of life of children with epilepsy affected by the education of mother.

NURSING IMPLICATIONS

The parents of epilepsy children face various psychological problem and financial burden while caring the sick child with chronic illness like epilepsy and also child take time to learn to live with such illness. So the educative counseling role of the nurse needs to be stressed for improving the quality of life of children with epilepsy. It can be fostered by reinforcing teaching to parent and children with epilepsy through planned teaching strategies i.e. group instruction , case scenario etc. This may motivate parents and children to provide comprehensive care and consistent in practicing self care activities respectively. A holistic approach is required to address this problem. There should be a link between hospital and community health nursing agencies to follow up the children with epilepsy to increase the child's compliance with treatment of epilepsy. Community health nurse in collaboration with NGO'S can organize the camps to foster the optimal growth and development of children with epilepsy and to develop ability to cope with the disease.

LIMITATION : The study was confined to small group of 60 children (30 children with epilepsy and 30 normal children with their parents) in selected area of saifai, Etawah. This limits the generalization of the findings.

RECOMMENDATIONS

- Longitudinal study can conducted to reveal more valuable, meaningful and important issues related to health related to quality of life in children with epilepsy.

CONCLUSION

- Normal children had better quality of life than epilepsy children as reported by children and parent.
- Quality of life of normal children and epilepsy children can be assessed by either of child report or parent report of Peds QL version 4 inventory

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