

# Assessment of Quality of Life in Children with Epilepsy

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**Abstract:** Epilepsy is a condition in which a person has recurrent seizures. As compared with other chronic condition, epilepsy has emotional and social health implication in addition to its physical effects, requiring those with epilepsy to adapt to social environments and to deal with emotional difficulties. **Objectives:** The study also aims to evaluate quality of life in children with epilepsy. **Methodology:** This is a cross-sectional observational study conducted for a period of 6 months in a tertiary care hospital setting. The caregivers of the patients were briefed about the study and consent was obtained to be recruited in the study. The collected data was entered in Microsoft excel and assessment quality of life was done. **Results:** A total of 86 caregivers were enrolled in the study based on the inclusion and exclusion criteria, out of which 52% were female and 48% were male. The mean age of our study subjects was found to be  $9.30 \pm 4.63$  yrs. Quality of life (QoL) of patient is a combined assessment of physical function, social function, emotional function, cognitive function. Majority of respondents 82.55% had quality of life score between 50-75%.

**Keywords:** Epilepsy, QoL, cross sectional study

## 1. Introduction

Epilepsy is a chronic disorder of the brain that affects people worldwide. It is characterized by recurrent seizures, which are brief episodes of involuntary movement that may involve a part of the body (partial) or the entire body (generalized), and are sometimes accompanied by loss of consciousness and control of bowel or bladder function.<sup>1</sup> A seizure is defined as a transient, involuntary alteration of consciousness, behavior, motor activity, sensation or autonomic function caused by an excessive rate and hyper synchrony of discharges from a group of cerebral neurons. The definition of status epilepticus refers to continuous or recurrent seizure activity lasting longer than 30 minutes without recovery of consciousness.

QOL has been defined by WHO as individual perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.<sup>2</sup> Chronic illnesses concern restrictions in functioning are either disease related or due to symptoms and treatment. Epilepsy is the most significant and prevalent chronic conditions in children. There is a growing concern about the problems that affect the lives of persons with chronic illnesses. Certain research has focused on specific problems (e.g., cognitive function in epileptic children) and has not systematically addressed the many dimensions of quality of life of persons with chronic morbidities. The limited research in this arena stimulated us to study the quality of life in children with epilepsy. Recent studies have revealed that parent-endorsed stress, worry, fears, and perceived stigma are predictors of parent-reported HRQOL in children with new-onset epilepsy.

There is lack of research on QOL among children with epilepsy from the developing countries, with only a few studies from India. The subscales affected by the age were energy/ fatigue, attention/concentration, language, anxiety and self-esteem. Partial epilepsy was found to impact the

levels of physical energy, social interaction and social activity more severely than generalized epilepsy. High seizure frequency or lesser time since last seizure was shown to adversely affect physical activity, memory, language and other cognitive faculties of the child. It was also found to significantly increase the levels of anxiety, decrease self-esteem and limit social interactions of the patient. It was noted to significantly alter the behavior, general health and the overall quality of life in such children.<sup>3</sup> recent studies reveal that age of the epileptic children was seen to affect the overall QOL and five subscales significantly. The lower self-esteem in older children may be because of the fact that older children may feel ashamed of their condition, and worry about social isolation. Children between 6-9 years of age scored better in the language domain. This is due to easier adaptability and greater learning skills in the younger age group. It was found that older adolescents reported a poorer overall HRQOL. QOL in 9-12 year olds is worse than younger children because younger children may be able to carry out more activities normally and not be hampered by epilepsy. Or they may not feel any lack of ability if there is restriction of any activity as much as 9-12 year olds. We feel 9-12 year olds have more adjustment problems than younger children or those 12-15 years old. 12-15 years' ones will have better understanding of the situation and disease, hence less impact on quality of life.<sup>4</sup>

We are measuring Quality of life using QOL-55 questionnaires: it is a 55 questionnaire scale, questions were divided into 4 categories Cognitive function (22 questions), Emotional function (17 questions), Social function (7 questions) and Physical function (9 questions).

## 2. Aim and Objectives

To assess the QoL Of children with epilepsy

### 3. Study Tools

- 1) **Data Collection Form:** Data will be collected by using a data collection form, which contains details like demography, chief complaints, history of present illness, medication and medical history.
- 2) **QOL Questionnaire:** It is a scale; where questions were divided into 4 categories Cognitive function, Emotional function, Social function and Physical function .

### 4. Results

This study includes a total of 86 caregivers drawn from the out-patient pediatric clinic at a tertiary care hospital which is a 500 bedded hospital with state of art facilities for patients.

Out of 86 responses received, majority of patients 56 (65.11%) belonged to children age group (2-12yrs). The mean age of our study population was found to be 9.30± 4.63years. Information is presented in figure 1.

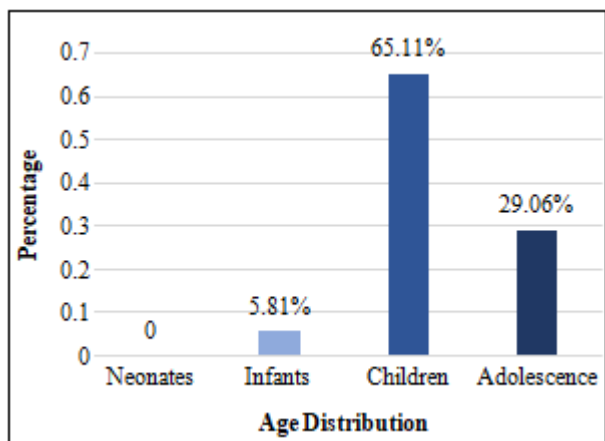


Figure 1: Age Distribution of patients (n=86)

Among the total responses received, majority of study population 52.32% were female and 42% male.

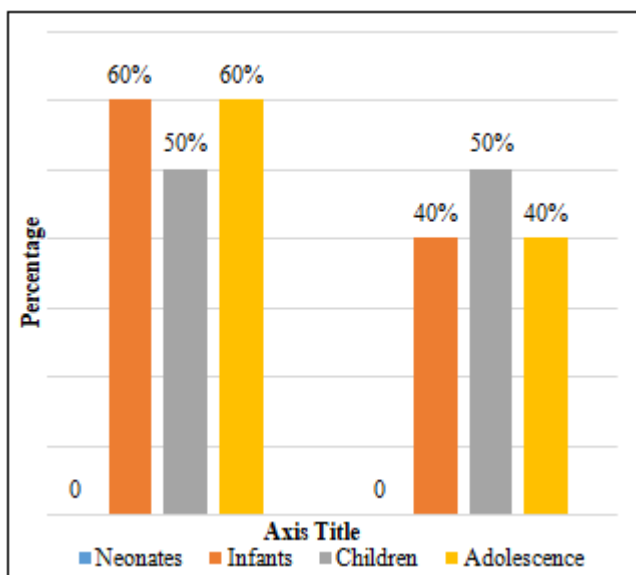


Figure 2: Age with Gender Distribution

Out of the total responses received there was equal distribution of male and female 50% in children age group

followed by adolescence and infants where 60% were male and 40% were female. There were no neonates in the study.

Out of 86 respondents enrolled in the study, it was found that first born children were found to have a slight dominance of 40.67% followed by second order 38.37%.

Out of total enrolled in the study, (89.43%) was found to be a case of non-hereditary.

Out of 86 respondents enrolled in the study 52.32 were diagnosed as GTCS (Generalized Tonic Clonic Seizure).

#### Interpretation of QoL (Quality of Life):

During the interpretation of the QoL, it was found that majority of the caregivers 82.55% had a good QoL ranging from 50-75%, around 1.16%(0-25%) had very low QoL, whereas 2.32% had moderate QoL (25-50%), and around 13.95% had a point range from (75-100%). This information is presented in figure 3

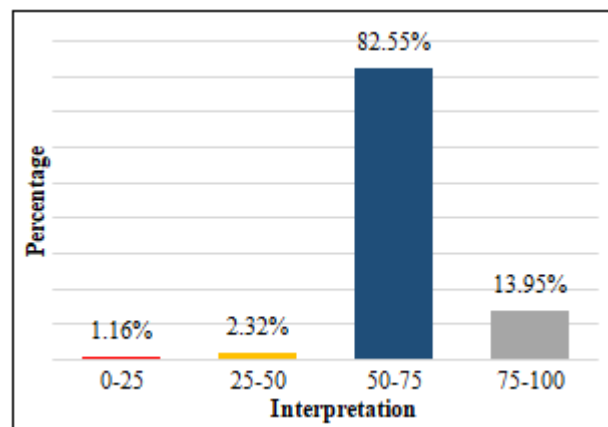


Figure 3: QoL (Quality of Life)

### 5. Discussions

The duration of the study was six-months, this cross-sectional study performed in the out-patient clinic of pediatric department. A total of 86 patients were enrolled in the study, based upon the inclusion and exclusion criteria. The study was conducted at tertiary care hospital.

The study uses USFDA age group as a parameter for classification of epileptic child. Majority of them, i.e. 65.11% belonged to children group, 29.06% belonged to adolescence group and 5.81% were infants group.

Among the responses received from caretakers there was slight prepondence was seen in female 52.32% in comparison to male 47.67%. In contrast with the studies conducted, **Teferi Jet al** in Ethiopia, showed male predominance 54.1% in comparison to female 45.9% of total population.<sup>5</sup>

Birth order of the children was taken into account. Most of the children in the study were of first born (40.67%) followed by second born (38.37%) child of their parent. This result is in contrast with other two studies, conducted by **Angelillo IF et al** in Italy<sup>6</sup> and **Roodpeyma S et al** in Iran<sup>7</sup>,

both found that children of second order 41.4% and 47.2% was suffering more from the disease.

QoL has been defined by WHO as individual perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a 55 questions scale; questions were divided into 4 categories Cognitive function (22 questions), Emotional function (17 questions), Social function (7 questions) and Physical function (9 questions) In chronic condition like epilepsy, the Quality of life (QoL) of the patient is highly affected. This is somewhat extended to the caregivers of the child as well in the QoL reported by the caregivers, it was found that the average QoL reported through QOLCE-55 by the caregivers was 68.08% which was almost similar to the study conducted by **Aggarwal A et al** "Quality of life in children with epilepsy, Delhi" where it was found to be 60% by using QOLCE-55. This study found that the patients socio-demographic variables had not significantly associated with caregiver's quality of life scores and also found that the correlation between the duration of illness and QoL were negative for all domains.<sup>2</sup>

## 6. Conclusion

In the present study, the responses received from caregivers, there was slight preponderance seen in female in comparison to male. Children age group (2-12) constitute to the most affected followed by adolescence. From the study it was also concluded that the first born were the most affected followed by second born child.

Generalised Tonic Clonic Seizure was the most common type of seizure observed in the study where majority of the responses stated that epilepsy was a brain disorder.

About 3/4<sup>th</sup> of the caregivers followed good practice towards the care of epileptic child. They had good practice while supervising medication and consulted physician when required.

Doctors and nurses were identified as main source of information regarding epilepsy to caregivers. Most of the caregivers were having satisfactory knowledge regarding epilepsy and also had positive attitude.

Efficient education programs should be implemented in order to ensure to impart knowledge and awareness can be created to improve quality of life in epileptic child. Systematically assessing patient's adherence to the drug regimen will improve the therapeutic outcome.

There is a need for providing patient caregivers counselling on use of drugs and adherence which will play a major role in achieving the required therapeutic outcome.

There was an increase in QoL with increasing age. Respondents from infants had lower QoL compared to Children and adolescence.

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