

Budapest International Research in Exact Sciences Medical, Biological, Argiculture, Engineering Science and other related areas

-ISSN - 2655-782 ISSN: 2655-7835

### **Quality of Life of Epileptic Children Using Pediatric "Quality** of Life Inventory" TM (PedsQLTM) Assessment at RSUD Dr. Zainoel Abidin Banda Aceh

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**Abstract:** Epilepsy is a chronic disease that causes social function barriers that affect quality of life. Clinical factors, demographics, psychosocial, and anti-epileptic drugs are reported to affect the quality of life of people with epilepsy. This study aims to assess the quality of life of children with epilepsy who seek treatment at the IKA section of RSUDZA. This research is an observational analytic study with a cross-sectional design at the neurology polyclinic and inpatient Dr. RSUD. Zainal Abidin Banda Aceh for the period April-May 2021. The research subjects are 2-18 years old. Quality of life assessment using generic PedsQLTM 4.0. Multivariate analysis was tested using logistic regression test. It was found that 60 epilepsy patients participated in the study and obtained a quality-of-life disorder based on parent reports of 28.3%, and children's reports of 34.1%. There was no statistically significant relationship between demographic factors and children's quality of life based on parental reports (p < 0.05). In the children's report, it was found that demographic factors in the form of unexpected parenting were risk factors for impaired quality of life (p < 0.05). Abnormal EEG picture is a clinically significant factor for impaired quality of life in children with epilepsy (p < 0.05). This study concludes that patients with risk factors namely unexpected parenting, abnormal EEG affect quality of life.

**Keywords:** *epilepsy; quality of life; PedsQLTM; parenting* 

### I. Introduction

Epilepsy as a chronic disease has an impact on the quality of life of patients. Quality of life is one of the important parameters in assessing the effectiveness of medical interventions (Forsgren, 2005; Sabaz, 2003; Christensen, 2007; Verhey, 2009; Suwarba, 2016). The incidence of epilepsy in children is reported from various countries with wide variations, around 4-8 per 1000 children, depending on the study design and age group of the population. Kidney disease has been experienced by humans since ancient times (Razi, 2021). There are at least 700,000 new cases in Indonesia each year and it is estimated that 40%-50% occur in children (Suwarba, 2016).

Clinical manifestations of epilepsy are acute and transient conditions such as decreased consciousness, motor, sensory, autonomic or psychic disturbances that are felt by the patient and can be witnessed by others. The main goal of the management of epilepsy in children is to make the family and patient experience minimal medical and psychosocial complications due to the disease. Wall et al (1987) reported that 77% of patients with epilepsy had difficulties in daily social functioning that affected their quality of life. Clinical factors, demographics, psychosocial, and anti-epileptic drugs (OAE) were reported to have a significant influence on the quality of life of people with epilepsy.

Quality of life is a subjective perception of a person's welfare on his life which includes

physical, psychological, and social domains (Matza, 2004). Chronic diseases that appear in childhood will affect the quality of growth and development, social function, emotion, physical, school ability lower than healthy children and affect the quality of life. Children's potential in the future (Eiser, 2009). Chronic disease according to WHO is a degenerative disease that develops or persists in a very long period of time, which is more than 6 months and requires medical treatment in dealing with health problems that limit what can be done. This condition also occurs in children with epilepsy whose main symptoms are seizures. Seizures in epilepsy greatly affect the quality of life of the sufferer, both in terms of education, development, as well as social or social interaction. Even if the patient experiences continuous seizures and is not treated, there can be damage or death of neuron cells in the brain which will later affect the level of intelligence and mental condition of the patient (Eiser, 2001; Major, 2007; Wishwadewa, 2008). If this has happened, of course, the quality of life of the patient will decrease and several studies have shown behavioral disorders such as depression, hyperactivity, and impaired school performance. Another factor that affects the quality of life is parenting. Parenting patterns are important in the survival of children because they are related to family, environment, and child care patterns (Ismail, 2011). A survey reported that 6-12% of children have chronic diseases. In this group some of them can adapt well, but the rest are not able to adapt and experience social, psychological, and social disturbances.

The type of parenting is divided into expected parenting, namely parenting from parents who are full of consideration and unexpected parenting, namely parenting that demands a lot and is dominant, parenting style from parents that gives complete freedom and only minimal parental intervention, and inconsistent parenting patterns (Ismail, 2011). The Child Parenting Questionnaire (KPAA) is a measuring tool to assess the parenting pattern obtained by parents, namely father and mother/guardian who live with the child. This questionnaire has a good Cronbach alpha that is 0.8347 with a correlation value showing a coefficient value between 0.0013-0.3979 which means that the correlation between units is quite item and good (Ismail, 2011).

Quality of Life in childhood epilepsy questionnaire parent form (QOLCE) was used as an instrument to assess the quality of life of children with epilepsy. This instrument was first developed by Sabaz et al in Australia which consists of 5 parameters to assess the quality of life, namely physical function, cognitive, emotional well-being, social function, and behavior. Other components include health stigma and general quality of life (Sabaz, 2000). Research on the quality of life of children with epilepsy using the QOLCE instrument has been conducted at RSCM Jakarta. In this study, it was found that the factors that affect the quality of life of children suffering from epilepsy are the number of seizures, the age of the child and the number of children in the family, while the number of epilepsy drugs consumed has no effect (Wishwadewa, 2008). The drawback of this instrument is that only parents/caregivers who have children suffering from epilepsy aged 4-18 years are included. Children are not included in this instrument. In QOLCE, because there are too many questions and it takes a long time, it is feared that respondents will give inappropriate answers, causing bias.

World Health Organization (WHO)set standards for measuring quality of life that include physical, mental, and social aspects. The pediatric quality inventoryTM (PedsQLTM) instrument is an instrument for measuring quality of life that meets these standards. This instrument consists of a generic module and a disease-specific module (Varni, 2020). The PedsQL 3.0 generic module instrument has been used on 25,000 children and their parents and has been translated into 60 languages. The PedsQLTM instrument has good reliability with a range of Cronbach values 0.73-0.94, a wide age range of 2-18 years, and there is an age grouping based on age subgroups. This questionnaire was asked for feelings felt during the last 30 days (Varni, 2020).

Based on the exposure to the data above, the researcher is interested in using PedsQLTM to determine the presence of disturbances or quality of life problems. This instrument in addition to having a subgroup of age groups, also has a wider age range, namely reports of parents 2-18 years old and children 5-18 years old. This reason is the basis for conducting this research so that interventions can be carried out as early as possible to achieve optimal quality of life.

### **II. Research Methods**

This research is an observational analytic study with a cross sectional design. The population of this study were all children with epilepsy who were undergoing treatment at the Regional General Hospital, dr. Zainoel Abidin Banda Aceh. The sample size in this study is calculated based on a single sample calculation to estimate the proportion of a population and obtained a minimum sample of 60 respondents. The research sample was determined by consecutive sampling with the application of exclusion criteria, namely Children have other chronic diseases that require special therapy, have psychiatric disorders, mental retardation, cerebral palsy, and severe disabilities, are not in optimal condition when data collection (currently experiencing acute illness, drowsiness) the patient's parents were not willing to participate in this study.

Parents were given an explanation that a research was being conducted on the quality of life of children with epilepsy based on the PedsQL<sup>TM</sup> measurement, as well as the purpose and benefits of the study. It was explained that there were two PedsQL<sup>TM</sup> questionnaires, namely child reports and parent reports. Reports for children aged 5-18 years and parents reports for children aged 2-18 years. The child's report will be asked to the child and filled in by the researcher, the parent's report will be filled in by the parent. It is explained that there is a KPAA questionnaire to assess parenting patterns. Questionnaires were filled out by parents. Parents were also asked to fill in demographic data in the research form.

The dependent variable (dependent) is the quality of life of Epileptic children as measured by PedsQL<sup>TM</sup>. The independent (independent) variables assessed are demographic factors (age, gender, parental education, children's education, parental occupation, family income level, and parenting). Clinical factors (type of epilepsy, EEG picture, duration of therapy), type of therapy (poly pharmacy, monopharmacy).

The data is processed using a statistical program. Univariate analysis describes descriptive results of various variables. Bivariant analysis using independent sample t test and Mann-Whitney U test was conducted to prove significant differences between parental reports and child reports. Meanwhile, multivariate analysis using logistic regression was carried out to obtain various factors related to quality of life.

### **III. Results and Discussion**

### **3.1 Results**

### a. The Basic Characteristics of the Research Sample

Not first

>2 kids

Expected

Father's education Base

Tall

Tall

Mother's job Work

dad's job Work

Not expected

Intermediate

Mother's education Base

Intermediate

Does not work

Does not work

Total family income Under UMR

Above UMR

Types of Epilepsy General

Focal

EEG overview

>2yrs

Normal Abnormal

Duration of therapy 2 yrs

Parenting

Number of children 2 kids

|                      | N(%)      |  |  |  |
|----------------------|-----------|--|--|--|
| Variable             |           |  |  |  |
| Gender               |           |  |  |  |
| Man                  | 50 (83.3) |  |  |  |
| Woman                | 10 (16.7) |  |  |  |
| AgeChild             |           |  |  |  |
| 2-4 years            | 19 (31.7) |  |  |  |
| 5-7 years            | 12(20,0)  |  |  |  |
| 8-12 years old       | 13 (21.7) |  |  |  |
| 13-18 years old      | 16 (26.7) |  |  |  |
| Children's Education |           |  |  |  |
| Not school yet       | 8 (13.3)  |  |  |  |
| Preschool            | 16 (26.7) |  |  |  |
| Low                  | 26 (43.3) |  |  |  |
| Intermediate         | 10 (16.7) |  |  |  |
| Child Order          | · · ·     |  |  |  |
| First                | 23 (38.3) |  |  |  |

37 (61.7)

37 (61.7)

23 (38.3)

39 (65.0)

21 (35.0)

16 (26.7)

37 (61.7)

7 (11.7)

13 (21.7)

33 (55.0)

14 (23.3)

58 (96.7)

2 (3,3)

14 (23.3)

46 (76.7)

45 (75.0)

15 (25,0)

38 (63.3)

22 (36.7)

42 (70.0)

18 (30,0)

23 (38.3)

37 (61.7)

 Table 1. The Basic Characteristics of the Research Sample

Based on Table 1, it is known that the majority of the subjects were male (83.3%) with the most age group being 2-4 years old (31.7%), followed by 13-18 years old 26.7%. Most of the children's education is of low education (43.3%) with the father's education being secondary (61.7%) and the mother being secondary (55%). More than half of the children with epilepsy studied in this study were not the first child and more than 60% of their families had only one or two children. Most of the fathers work (96.7%) and only 23.3% of mothers who work. Most of the patients' socioeconomic status (75%) came from the lower middle class, indicated by the total family income below the minimum wage. 65% of the subjects received the expected parenting style. The longest duration of therapy was found to be >2 years (61.7%). Treatment with polypharmacy found 12% and monopharmacy 48%. Most children had normal EEG findings (70%), 30% with abnormal features. Epileptic children studied in this study 63.3% had generalized epilepsy, 36.7% had focal epilepsy.

## b. The Description of the Average Value of the Components of the Quality Of Life of Children with Epilepsy According to the Questionnaire Assessment PedsQL<sup>TM</sup>

| Variable                     | Parent           | Child            | p-value |
|------------------------------|------------------|------------------|---------|
|                              | (Average ± SD)   | (Average ± SD)   | 1       |
| Physical Function            | 77.09±5.12       | $78.23 \pm 4.16$ | 0.201b  |
| Emotional Function           | $74.08 \pm 6.39$ | $74.40\pm5.74$   | 0.791a  |
| Social Function              | $75.07 \pm 6.20$ | $74.24\pm5.68$   | 0.769b  |
| School Function              | $61.56\pm28.55$  | $75.26\pm6.59$   | 0.023b  |
| <b>Psychosocial Function</b> | $74.91 \pm 4.60$ | $74.70\pm3.93$   | 0.810a  |

**Table 2.** A Comparison of the Value of Each Function of the Quality of Life of

 Children with Epilepsy between the Sources of Parental Reports and Child Reports

Table 2 presents a comparison of the value of each function of the quality of life of children with epilepsy between the sources of parental reports and child reports. Based on Table 2, it is known that 2 of the 5 components of the quality of life of children with epilepsy have a higher average value based on parental reports when compared to children's reports. The two components are social function and psychosocial function. Meanwhile, the average score of the components of physical, emotional and school functions based on children's reports looks higher than according to parents' reports. However, further testing with Independent sample t test and Mann-Whitney U test proved that only school function in epilepsy children was significantly different between parent reports and child reports. This is indicated by the p-value of the test which is smaller than 0.05 in the comparison of school function scores between the two report sources (parents and children). Meanwhile, the other four components of children's quality of life (physical, emotional, social and psychosocial functions) were not significantly different between parent reports and children's reports.

Based on Table 3 shows that in general the number of children with epilepsy who have a quality of life in the impaired category is less than the number of children who are not affected by their quality of life based on parental assessment reports. Their parents were analyzed by logistic regression model. There was no significant relationship between demographic factors and children's quality of life based on parental reports using PedsQL<sup>TM</sup> (p>0.05).

|                      | Children's quality | y of life based |           |                            |
|----------------------|--------------------|-----------------|-----------|----------------------------|
| Variable             | on parental        | reports         | - n value | Odda Patio (059/ CI)       |
| v al lable           | Not distrubed      | Disturbed       | - p-vaiue | <i>Oaas Kallo</i> (95% CI) |
|                      | (N)                | (N)             |           |                            |
| Gender               |                    |                 |           |                            |
| Man                  | 35                 | 15              | -         | 1                          |
| Woman                | 8                  | 2               | 0.525     | 0.583 (0.111-3.078)        |
| AgeChild             |                    |                 |           |                            |
| 2-4 years            | 16                 | 3               | -         | 1                          |
| 5-7 years            | 7                  | 5               | 0.120     | 3,810 (0.707-20,533)       |
| 8-12 years old       | 10                 | 3               | 0.606     | 1,600 (0.269-9.533)        |
| 13-18 years old      | 10                 | 6               | 0.153     | 3,200 (0.649-15.75)        |
| Children's Education |                    |                 |           |                            |
| Not school yet       | 6                  | 2               | -         | 1                          |
| Preschool            | 12                 | 4               | 1,000     | 1,000 (0.141-7.099)        |
| Low                  | 19                 | 7               | 0.914     | 1.105 (0.179-6.821)        |
| Intermediate         | 6                  | 4               | 0.505     | 2,000 (0.260-15.381)       |
| Child Order          |                    |                 |           | , , ,                      |
| First                | 15                 | 8               | -         | 1                          |
| Not first            | 28                 | 9               | 0.384     | 0.603 (0.193-1.885)        |
| Number of children   |                    |                 |           |                            |
| 2 kids               | 25                 | 12              | -         | 1                          |
| >2 kids              | 18                 | 5               | 0.374     | 0.579 (0.173-1.934)        |
| Parenting            |                    |                 |           |                            |
| Expected             | 18                 | 3               | -         | 1                          |
| Not expected         | 25                 | 14              | 0.087     | 3,360 (0.840-13,441)       |
| Father's education   |                    |                 |           | ,                          |
| Base                 | 13                 | 3               | 0.999     | NA                         |
| Intermediate         | 23                 | 14              | 0.999     | NA                         |
| Tall                 | 7                  | 0               | -         | 1                          |
| Mother's education   |                    |                 |           |                            |
| Base                 | 8                  | 5               | 0.077     | 8.125 (0.798-82.731)       |
| Intermediate         | 22                 | 11              | 0.089     | 6,500 (0.750-56,300)       |
| Tall                 | 13                 | 1               | -         | 1                          |
| dad's job            |                    |                 |           |                            |
| Work                 | 42                 | 16              | -         | 1                          |
| Does not work        | 1                  | 1               | 0.504     | 2.625 (0.155-44.526)       |
| Mother's job         |                    |                 |           |                            |
| Work                 | 10                 | 4               | 0.982     | 1.015 (0.270-3.821)        |
| Does not work        | 33                 | 13              | -         | 1                          |
| Total family income  |                    |                 |           |                            |
| Under UMR            | 30                 | 15              | 0.152     | 3,250 (0.648-16,301)       |
| Above UMR            | 13                 | 2               | -         | 1                          |

**Table 3.** The Relationship between Demographic Factors and Quality of Life of Children with Epilepsy Based on Parental Reports

# c. The Relationship between Demographic Factors Andquality of Life of Children with Epilepsy Based on Reports of Children Using PedsQL<sup>TM</sup>

**Table 4.** The Relationship between Demographic Factors Andquality of Life of Children with Epilepsy Based on Reports of Children Using PedsQL<sup>TM</sup>

|          |          | 1  | U       | •                   |
|----------|----------|--|---------|---------------------|
| Variable | Childror | en's quality of life based<br>1 children's reports | p-value | Odds Ratio (95% CI) |
|          |          |  |         |                     |

|  | Not uisti ubeu   | Disturbed   |   |   |
|--|--|---|---|---|
|  | (N)  | (N)   |   |   |
| ender  |  |   |   |   |
| Man  | 21   | 13  | -   | 1   |
| Woman  | 6  | 1   | 0.248   | 0.269 (0.029-2.497)   |
| geChild  |  |   |   |   |
| 5-7 years  | 7  | 5   | -   | 1   |
| 8-12 years old   | 11   | 2   | 0.157   | 0.255 (0.038-1.692)   |
| 13-18 years old  | 9  | 7   | 0.912   | 1.089 (0.240-4.950)   |
| ildren's Education   |  |   |   |   |
| Preschool  | 3  | 2   | -   | -   |
| Low  | 19   | 7   | 0.559   | 0.553 (0.076-4.035)   |
| Intermediate   | 5  | 5   | 0.715   | 1,500 (0.170-13,225)  |
| ild Order  |  |   |   |   |
| First  | 13   | 6   | -   | 1   |
| Not first  | 14   | 8   | 0.747   | 1.238 (0.337-4.543)   |
| umber of children  |  |   |   |   |
| 2 kids   | 18   | 9   | -   | 1   |
| >2 kids  | 9  | 5   | 0.879   | 1.111 (0.287-4.306)   |
| renting  |  |   |   | ``````````````````````````````````````  |
| Expected   | 12   | 1   | -   | 1   |
| Not expected   | 15   | 13  | 0.034   | 10,400 (1,186-91,176)   |
| ther's education   |  |   |   |   |
| Base   | 7  | 7   | 0.999   | NA  |
| Intermediate   | 15   | 7   | 0.999   | NA  |
| Tall   | 5  | 0   | -   | 1   |
| other's education  |  |   |   |   |
| Base   | 2  | 3   | 0.999   | NA  |
| Intermediate   | 15   | 11  | 0.999   | NA  |
| Tall   | 10   | 0   | -   | 1   |
| d's job  | - •  | -   |   | -   |
| Work   | 26   | 13  | -   | 1   |
| Does not work  | 1  | 1   | 0.634   | 2.000(0.116-34.598)   |
| other's job  | -  | -   | 0.001   | _,  |
| Work   | 9  | 3   | 0.430   | 0.545 (0.121-2.461)   |
| Does not work  | 18   | 11  | -   | 1   |
| tal family income  |  | - •   |   |   |
| Under UMR  | 13   | 14  | 0.998   | NA  |
| Above UMR  | 14   | 0   | -   | 1   |
| geChild<br>5-7 years<br>8-12 years old<br>13-18 years old<br>iildren's Education<br>Preschool<br>Low<br>Intermediate<br>iild Order<br>First<br>Not first<br>Imber of children<br>2 kids<br>>2 kids<br>renting<br>Expected<br>Not expected<br>ther's education<br>Base<br>Intermediate<br>Tall<br>other's education<br>Base<br>Intermediate<br>Tall<br>other's education<br>Base<br>Intermediate<br>Tall<br>other's job<br>Work<br>Does not work<br>other's job<br>Work<br>Does not work<br>tal family income<br>Under UMR<br>Above UMR | $ \begin{array}{c} 7\\ 11\\ 9\\ 3\\ 19\\ 5\\ 13\\ 14\\ 18\\ 9\\ 12\\ 15\\ 7\\ 15\\ 5\\ 2\\ 15\\ 10\\ 26\\ 1\\ 9\\ 18\\ 13\\ 14\\ \end{array} $ | $ \begin{array}{c} 5\\2\\7\\\\2\\7\\\\5\\\\6\\8\\\\9\\5\\\\1\\1\\3\\\\1\\\\0\\\\13\\\\1\\\\0\\\\13\\\\1\\\\3\\\\11\\\\1\\\\1\\\\1\\\\1\\\\1\\\\1\\\\1\\\\1\\\\$ | 0.157<br>0.912<br>-<br>0.559<br>0.715<br>-<br>0.747<br>-<br>0.879<br>-<br>0.034<br>0.999<br>0.999<br>-<br>0.999<br>-<br>0.999<br>-<br>0.634<br>0.430<br>-<br>0.998<br>- | 1<br>0.255 (0.038-1.692)<br>1.089 (0.240-4.950)<br>-<br>0.553 (0.076-4.035)<br>1,500 (0.170-13,225)<br>1<br>1.238 (0.337-4.543)<br>1<br>1.111 (0.287-4.306)<br>1<br>10,400 (1,186-91,176)<br>NA<br>NA<br>1<br>NA<br>NA<br>1<br>1<br>2,000 (0.116-34.598)<br>0.545 (0.121-2.461)<br>1<br>NA<br>1 |

The results of the logistic regression analysis in Table 4 show that only 1 of 11 independent variables has a significant effect on the quality of life of children with epilepsy. The independent variable that affects the quality of life of children with epilepsy is parenting with an Odds Ratio of 10,400 (95% confidence interval lies between1,186 to 91,176). This indicates that children with epilepsy with unexpected parenting are 10.4 times more likely to have a disturbed quality of life when compared to children with epilepsy who have expected parenting.

**Table 5.** The Relationship between Clinical and Quality of Life of Children with EpilepsyBased on Parental Reports Using PedsQL<sup>TM</sup>

|          | 1 0   | <u> </u> |                     |
|----------|---|----------|---------------------|
| Variable | Children's quality of life based<br>on parental reports | p-value  | Odds Ratio (95% CI) |
|          |   |          |                     |

|                     | Not distrubed<br>(N) | Disturbed<br>(N) | -     |                      |
|---------------------|----------------------|------------------|-------|----------------------|
| Types of Epilepsy   |                      |                  |       |                      |
| General             | 27                   | 11               | 0.890 | 1.086 (0.337-3.505)  |
| Focal               | 16                   | 6                | -     | 1                    |
| EEG overview        |                      |                  |       |                      |
| Normal              | 34                   | 8                | -     | 1                    |
| Abnormal            | 9                    | 9                | 0.018 | 4,250 (1,276-14,151) |
| Duration of therapy |                      |                  |       |                      |
| 2 yrs               | 18                   | 5                | -     | 1                    |
| >2yrs               | 25                   | 12               | 0.374 | 1,728 (0.517-5,774)  |

Based on Table 5, a significant relationship was found on the EEG picture with quality of life based on parental reports (p < 0.05) with an Odds Ratio (OR) of 4.250. This indicates that children with epilepsy who have an abnormal EEG category tend to be 4.25 times more likely to have a disturbed quality of life when compared to children with epilepsy who have a normal EEG picture.

| Variable            | Children's qualit<br>on children's | y of life based<br>s reports | n value | Odds Ratio (95% CI)  |
|---------------------|------------------------------------|------------------------------|---------|----------------------|
|                     | Not distrubed<br>(N)               | Disturbed<br>(N)             | p-value |                      |
| Types of Epilepsy   |                                    |                              |         |                      |
| General             | 16                                 | 8                            | 0.896   | 0.917 (0.248-3.389)  |
| Focal               | 11                                 | 6                            | -       | 1                    |
| EEG overview        |                                    |                              |         |                      |
| Normal              | 22                                 | 7                            | -       | 1                    |
| Abnormal            | 5                                  | 7                            | 0.042   | 4,400 (1,055-18,358) |
| Duration of therapy |                                    |                              |         |                      |
| 2 yrs               | 7                                  | 4                            | -       | 1                    |
| >2yrs               | 20                                 | 10                           | 0.856   | 0.875 (0.206-3.708)  |

**Table 6.** The Relationship between Clinical and Quality of Life of Children with Epilepsy

 Based on Reports of Children Using PedsQL<sup>TM</sup>

Based on Table 6, a significant relationship was found on the EEG picture with the quality of life based on the child's report (p < 0.05) with an OR of 4,400. This shows that children with abnormal EEG images tend to be 4.4 times more likely to have a disturbed quality of life when compared to children with epilepsy who have normal EEG features.

| Children's quality of life based  |  |
|---|--|
| Based on Parental Reports Using PedsQL <sup>TM</sup>  |  |
| <b>Table 7.</b> Relationship between Therapies with Quality of Life of Children with Epilepsy |  |

| Variable           | Children's quality<br>on parental | y of life based<br>reports | n nalua   | Odda Datia (050/ CI)        |
|--------------------|-----------------------------------|----------------------------|-----------|-----------------------------|
|                    | Not distrubed<br>(N)              |                            | - p-vaiue | <i>Jaus Kallo</i> (95 % C1) |
| Type of Therapy    |                                   |                            |           |                             |
| Polypharmacy       | 7                                 | 5                          | 0.258     | 2,143 (0.572-8.026)         |
| Monopharmaceutical | 36                                | 12                         | -         | 1                           |

There was no significant relationship between the type of therapy while participating in the study and the quality of life based on parental reports (p>0.05)

| Based on Reports of Children Using Fedsqu |   |                  |           |                              |  |
|---|---|------------------|-----------|------------------------------|--|
| Variable                                  | Children's quality of life based<br>on children's reports |                  | n valuo   |                              |  |
|   | Not distrubed<br>(N)                                      | Disturbed<br>(N) | – p-vaiue | <i>Guus Kuub (93 /</i> 8 CI) |  |
| Type of Therapy                           |   |                  |           |                              |  |
| Polypharmacy                              | 6   | 6                | 0.175     | 2.625 (0.651-10.583)         |  |
| Monopharmaceutical                        | 21  | 8                | -         | 1                            |  |

**Table 8.** Relationship between Therapies with Quality of Life of Children with Epilepsy

 Based on Reports of Children Using Pedsql<sup>tm</sup>

Based on table 8 there was no significant relationship between the type of therapy while participating in the study and the quality of life based on children's reports (p>0.05).

### **3.2 Discussion**

This study is the first study to assess the quality of life of children with epilepsy using the PedsQL<sup>TM</sup> questionnaire in epilepsy children undergoing treatment at the Neurology polyclinic and inpatient section of the RSUDZA Banda Aceh. The PedsQL<sup>TM</sup> questionnaire is a questionnaire that is easy to use, inexpensive, can be used by other medical personnel, meets the requirements for the feasibility of the instrument to be used to assess quality of life, such as having high validity and reliability and has been proven in several studies, available in generic and specific forms. , can be filled out by the child (self-report) or parent/guardian (proxy report), and is available for various age groups, and this questionnaire has been translated into several language versions with the aim of facilitating its implementation (Modi, 2017; Katherine, 2016; Aji, 2016).

The majority of male subjects were involved in this study.Based on gender, men had a higher risk of suffering from epilepsy, but no racial differences were found (Ali, 2007; Mohammed, 2005). The incidence was higher in men, similar to the study in Turkey found 59.3% of men, as a risk factor for epilepsy (odds ratio 1.38; 95% internal confidence 1.13-1.69) (Ali, 2007; Aydin, 2002).

In this study, from parental reports, it was found that family demographics were not a factor influencing the quality of life of children with epilepsy. There were previous studies that looked for factors that influenced children's quality of life with different results. In a study using the QOLCE instrument, although family demographics did not affect the overall quality of life of children, in the group of parents with good income, children tend to have better self-confidence and can affect emotional functioning. The higher the education history and family income, the treatment is routine. Thus, the patient's neurological function improvement can be achieved. The patient becomes more confident and anxiety in activities is reduced (Wishwadewa, 2018). There are also studies that report similar results with this study.

The effect of parental income on the quality of life of pediatric epilepsy patients in this study was not significant because it was caused by other confounding variables. In this case, the participation of the Social Security Administering Body (BPJS) is a factor that is considered to have an influence. BPJS health participation helps treat pediatric epilepsy patients so that it does not only depend on the socioeconomic conditions of the family. According to the research report of Saing (2010), financial problems are the reason that causes treatment irregularities in 20% of the tested samples. All subjects (100%) are BPJS participants, so the results of our study cannot provide an overview for the non-BPJS group.

Children's reports show a significant relationship between unexpected parenting patterns and impaired quality of life for children. In a previous study conducted at the RSCM using the QOLCE instrument aged 4-18 years, it showed that the average parent/caregiver anxiety was significantly correlated with the child's anxiety. Caregivers who are not good about epilepsy, resulting in a parenting pattern that tends to be overprotective to patients. Williams et al24 reported that in two different disease groups, namely epilepsy and diabetes, it was found that parenting patterns of parents were worried about having seizures at night, resulting in different parenting patterns that affected anxiety and quality of life in children with epilepsy.

Although epilepsy is a clinical diagnosis, electroencephalography (EEG) is a very important examination to confirm the diagnosis of epilepsy, determine the classification of epilepsy, see the epileptogenic focus, evaluate the results of therapy, and determine the prognosis (Mohammed, 2002; Doescher, 2006). EEG examination is also very necessary to rule out the possibility of epilepsy-like disorders such as syncope, breath holding speech, infantile masturbation. migraine and so on. which often make epilepsy misdiagnosed/overdiagnosed (Kurukawa, 2010; Doose, 1997; Noachtar, 2009). The first EEG recording in this study, abnormal images were obtained in 30% of cases and the majority of the remaining EEG images were within normal limits. Several other studies reported similar results, the first EEG was abnormal in 37-39% of cases (Doescher, 2006; Doose, 1997; Jaseja, 2009).

The results of EEG recordings are influenced by many factors and not always impaired brain function can be reflected in EEG recordings. Normal EEG findings can be found in children with epilepsy, whereas mild and atypical EEG abnormalities are present in 15% of the normal population.<sup>29.32</sup>Abnormal EEG images in this study were found to be fewer than normal EEGs, because only the first EEG recording was recorded when epilepsy was diagnosed, and the recording was performed when the patient was not having seizures (inter-ictal). In the literature it is stated that abnormal EEG images will be obtained more often if the EEG is repeated several times.<sup>10.33</sup>In addition, these results differ because to obtain a positive result requires several activation procedures, such as sleep, hyperventilation, and photic stimulation (Deroos, 2009; Shinnar, 1996).

Abnormal EEG images in this study had a significant relationship with impaired quality of life (p < 0.05), this was different from the previous study by Winny et al, and Vicra et al. lives of children with epilepsy.

In this study the relationship between therapeutic factors and children's quality of life, both parental reports and child reportsshowed that children who used monopharmaceutical treatment had a better effect on the patient's quality of life than polypharmacy treatment. Previously, various studies did report the effect of the type of OAE administration on the patient's quality of life, but the effect varied between studies. polypharmacy is considered to encourage the improvement of the patient's quality of life (Piperidou, 2008; Dash, 2015). It is also said that in patients with intractable epilepsy, polypharmacy treatment is able to reduce the frequency of seizures which can later affect the patient's quality of life (Dash, 2015). Others reported the same results as this study, where patients who received monopharmacy treatment had a better quality of life score compared to patients who received polypharmacy treatment. impaired quality of life when compared with children with epilepsy with monotherapy, as well as in children's reports showing that children treated with polypharmacy have an OR value of 2.625, meaning that they tend to be 2.62 times more likely to have impaired quality of life than children treated with monopharmaceuticals.1 time to have a disturbed quality of life when compared to children with epilepsy with monotherapy, as well as reports from children showing that children treated with polypharmacy had an OR value of 2.625, meaning that they tended to be 2.62 times to have a disturbed quality of life compared to children with monopharmaceutical therapy. 1 time to have a disturbed quality of life when compared to children with epilepsy with monotherapy, as well as reports from children showing that children treated with polypharmacy had an OR value of 2.625, meaning that they tended to be 2.62 times to have a disturbed quality of life compared to children with monopharmaceutical therapy.

Some types of OAE can cause side effects in patients, such as central nervous system-related disorders, decreased motor and psychomotor activity, low memory, and difficulty concentrating. Adequate treatment for patients, although seizure-free is an important goal in the treatment of epilepsy, the side effects of drugs and the effect on the patient's quality of life also need to be considered (Auriel, 2009; Elsharkawy, 2012; Dang, 2017).

### **IV.** Conclusion

There is a difference in the value of each function of the quality of life of children with epilepsy between the source reports of parents and children's reports. Disturbed quality of life is obtained from parental reports of 28.3%, and children's reports of 34.1%. There is a significant relationship between demographic factors in the form of unexpected parenting with the occurrence of impaired quality of life in children with epilepsy based on children's reports, abnormal EEG is a clinical factor that has a significant relationship with impaired quality of life in children with epilepsy according to reports from parents and children using a questionnaire PedsQLTM.

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