

Quality of life epilepsy in childhood: Comparison between well-controlled epilepsy and non epilepsy

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ABSTRACT

Quality of life is an important parameter in assessing the efficacy of medical interventions. Chronic diseases such as epilepsy, have a significant impact on quality of life. Childhood epilepsy is often associated with low achievement in school, physical limitations, and disturbed social functions. The purpose of this study was to compare the quality of life of well-controlled epileptic children with non epileptic children. This research was conducted with cross-sectional study design with respondents aged 5-18 years old. All respondents were well-controlled epileptic and non epileptic children who were admitted to the Pediatric Polyclinic of Dr. Sardjito General Hospital, Yogyakarta, Indonesia in the period of March until June 2010. Measurement of quality of life was conducted by filling out the questionnaire Pediatrics Quality of Life (PedsQL) that directly obtained from the children who were accompanied by their parent. Lower total score of PedsQL showed better quality of life. The results showed that mean total score of PedsQL on well-controlled epileptic children (38.31 ± 1.6) was higher than non epileptic children (8.84 ± 0.90). Prevalence ratio of controlled epileptic children was 2.69 (95% CI: 2.01-3.58). In conclusion, well-controlled epileptic children had lower quality of life than non epileptic children. The factors that affect quality of life of well-controlled epileptic children were duration of suffering from epilepsy and age at diagnosis of epilepsy.

Key words: quality of life – well-controlled epileptic children - PedsQL – physical function – emotional function- social function

ABSTRAK

Kualitas hidup merupakan salah satu parameter penting dalam menilai efikasi intervensi medis. Penyakit kronis seperti epilepsi mempunyai dampak terhadap kualitas hidup penderita. Epilepsi pada anak berhubungan dengan prestasi rendah di sekolah, keterbatasan fisik, dan gangguan fungsi sosial. Penelitian ini dilakukan dengan tujuan mengetahui perbedaan kualitas hidup anak dengan epilepsi terkontrol dengan anak normal tidak menderita epilepsi. Penelitian menggunakan rancangan potong lintang pada responden anak usia 5-18 tahun. Seluruh responden merupakan anak yang datang di Poliklinik Anak Rumah Sakit Umum Pusat Dr. Sardjito, Yogyakarta selama bulan Maret 2010 sampai Juni 2010. Pengukuran kualitas hidup dilakukan melalui pengisian kuesioner PedsQL oleh anak secara langsung didampingi orang tuanya. Nilai total PedsQL yang lebih rendah menunjukkan kualitas hidup yang lebih baik. Hasil penelitian menunjukkan nilai total PedsQL anak dengan epilepsi terkontrol lebih tinggi ($38,31 \pm 1,60$) dibandingkan dengan anak tidak epilepsi ($8,84 \pm 0,90$). Rasio prevalen anak dengan epilepsi terkontrol adalah 2,69 (CI 95%: 2,01-3,58). Dapat disimpulkan bahwa anak dengan epilepsi terkontrol mempunyai kualitas hidup lebih rendah dibanding anak tidak epilepsi. Faktor-faktor yang mempengaruhi kualitas hidup anak epilepsi terkontrol adalah lama menderita epilepsi dan usia saat terdiagnosis sebagai penderita epilepsi.

Kata kunci : kualitas hidup-epilepsi terkontrol-PedsQL-fungsi fisik-fungsi emosi-fungsi sosial

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INTRODUCTION

Epilepsy in childhood correlates with lower school achievement, mental disability, lower social competency, lower social contact, higher psychological and behavior problems. Discrepancy in quality of life relates with some epileptic variables, such as the frequency, severity, type and etiology of seizure, age of onset of epilepsy, intellectual disability, cognitive impairment and antiepileptic drug.¹

Quality of life is the most important parameter to evaluate medical intervention, therefore mortality is not the only parameter.² World Health Organization's (WHO's) work frame suggests that focuses of health are environment and personal factors. Moreover, the main aims of health are activities and social participations. Health has two indicators, which are objective indicators such as functional status, activities and participation, and also subjective indicator such as health-related quality of life.³

Epilepsy is serious neurologic disease in childhood. Epilepsy interferes psychosocial function and quality of life of the patients.⁴ It relates with psychosocial consequences, however usually do not relate with the clinical manifestation. Many negative consequences follow children with epilepsy.⁵ It make us interested to conduct research with self-report quality of life. The aim of this research was to determine the difference of quality of life between well-controlled epileptic children and non epileptic children.

MATERIALS AND METHODS

This was cross sectional study design. The main result was the difference scores on the Indonesian PedsQL. Measurements of quality of life were performed on the variable level of quality of life and the factors that may influence.

Subjects

Subjects of this study were well-controlled epileptic children and children with mild infection but no history of epilepsy, febrile seizures and other chronic diseases, with aged 5-18 years old who

admitted to the Pediatric Polyclinic of Dr. Sardjito General Hospital, Yogyakarta. The sample size needed for this study was calculated according to the mean hypothesis test with a difference of two hypotheses in one direction, therefore the sample size of this study was 98 children. The inclusion criteria were children who were still in the treatment of epilepsy, had no seizures in the last one year, did check up at the Pediatric Neurology Clinic of Dr. Sardjito General Hospital Yogyakarta, aged between 5-18 years and parents allowed the participation of subjects in the study as demonstrated by signing an informed consent. The exclusion criteria were patients who had neurological disorders, psychiatric disorders, other chronic diseases, were hospitalized for any cause, and did not living with her or his parents. The research was conducted at the Pediatric Neurology Clinic Dr. Sardjito General Hospital, Yogyakarta since March until June 2010. Consecutive sampling was used to collect all samples. The protocol of this research was approved by the Medical and Health Research Committee, Faculty of Medicine, Gadjah Mada University, Yogyakarta.

Data analysis

Data were obtained from the subjects using questionnaires filled in directly by the respondents and from medical records. Translation and validation of PedsQL in Indonesian version were conducted and Cronbach's α coefficient was measured to know the internal consistency. The result found that the Cronbach's α coefficient was ≤ 0.7 indicating the Indonesian version questionnaire of PedsQL was reliable. A previous study conducted by Sitaresmi *et al.* had tested the reliability of the results of this questionnaire with $\alpha = 0.86$ showing that the questionnaire was reliable.⁶

Data analysis used in this study included (a) univariate analysis by test, (b) unpaired t test to measure the difference of mean score of quality of life between well-controlled epileptic and non epileptic children, (c) logistic regression analysis to assess the factors that affect the quality of life of well-controlled epileptic children. Significance level used in this study was $p < 0.05$. A computer program was used to process the data.

RESULTS

A total of 100 children who met the inclusion criteria was obtained, but two children were excluded because they could not fulfill or complete the needed data or the parent and child were not cooperative. Therefore this study enrolled 49 well-controlled epileptic children and 49 non epileptic children. After the parents signed the informed consent, the filling of questionnaire was conducted.

Data characteristics

TABLE 1 showed significant differences in family income, method of payment, and the number of children. These three variables were associated with socio-economic level which was assumed to have an impact on the quality of life of children.

TABLE 1. Characteristics of subjects

Variable	Well-controlled epilepsy (n=49) or %	Non epilepsy (n=49) or %
Gender		
• Boys	40 (81.63)	40 (81.63)
• Girls	9 (18.37)	9 (18.37)
Age group		
• 5-7 years	22 (44.90)	20 (40.82)
• 8-18 years	27 (55.10)	29 (59.18)
Family income		
• ≤ IDR 700.000.-	21 (42.86)	0 (0)
• > IDR 700.000.-	28 (57.14)	49 (100)
Payment methods		
• Health insurance	46 (93.88)	6 (12.24)
• General	3 (6.12)	43 (87.76)
Mather's education*		
• Low	21 (42.86)	16 (32.65)
• High	28 (57.14)	33 (67.35)
Mather's occupation		
• Unemployed	19 (38.77)	23 (46.94)
• Work	30 (61.23)	26 (53.06)
Number of children		
• ≤ 2	28 (57.14)	4 (8.16)
• >2	21 (42.86)	45 (91.84)

* Low : elementary/junior school graduate; High: high school/university graduate

Factors affecting the level of quality of life in children

The result of logistic regression analysis on the variables of family income, health care payment and number of children was differ strikingly, and it can be concluded that those variables were not affecting the quality of life of children. Because there was no correlation between demographic factor and quality of life, the risk factor was probably epilepsy itself. This can be calculated by prevalence ratio. Prevalence ratio calculation result was 2.69 (CI95%: 2.01-3.58). The value of the confidence interval

was more than 1, therefore epilepsy, although already controlled, was a risk factor of poor quality of life.⁷

Differences in quality of life of well-controlled epileptic children and non epileptic children

Assessment of quality of life based on the PedsQL questionnaire showed that higher total score of PedsQL indicated poor in quality of life (TABLE 2). The results showed that the average quality of life for well-controlled epileptic children was significantly lower than non epileptic children

($p < 0.01$). It was also consistently seen in each and every function that represented the quality of life of children. Functions that were affected in well-controlled epileptic children were functions of physical, school, social and emotional. While in the

group of non epileptic children, school function was the most dominant disrupted function, followed by physical, and emotional functions, while social function was not disrupted function.

TABLE 2. Mean score of PedsQL

Variable	Well-controlled epileptic children (mean±SD)	Non epileptic children (mean±SD)	p
Total score of PedsQL	38.31 ± 1.60	8.84 ± 0.90	< 0.01
Physical function	13.26 ± 2.40	1.96 ± 0.20	< 0.01
Emotional function	5.86 ± 0.35	1.90 ± 0.30	< 0.01
Social function	8.57 ± 0.90	0.00 ± 0.00	< 0.01
School function	10.61 ± 0.91	4.98 ± 0.78	< 0.01

TABLE 3 showed poor quality of life for well-controlled epileptic children than non epileptic children. In younger children (aged 5-7 years old), the average total score of PedsQL for well-controlled epileptic children was higher than the average total score of overall PedsQL of non epileptic children ($p < 0.01$). Moreover, TABLE 4 also showed that in older children (aged 8-18 years old) the average

total score of PedsQL in well-controlled epileptic children was higher than the average total score of PedsQL in non epileptic children ($p < 0.01$). These score indicated that both in the younger and older children, the quality of life of well-controlled epileptic children was significantly lower than non epileptic children ($p < 0.01$).

TABLE 3. Mean score of PedsQL in children aged 5-7 years old

Variable	Well-controlled epileptic children (mean±SD)	Non
Total score of PedsQL	39.09 ± 1.34	
Physical function	14.36 ± 2.27	
Emotional function	6.00 ± 0.00	
Social function	8.54 ± 0.91	
School function	10.18 ± 0.58	

Table 4. Mean score quality of life (age 8-18 years)

Variable	Well-controlled epilepsy mean (SD)	Non epilepsy mean (SD)	p
Score total PedsQL	37.67 (1.52)	8.45 (0.63)	<0.01*
Physical function	12.37 (2.15)	1.93 (0.26)	<0.01*
Emotional function	5.74 (0.45)	1.83 (0.38)	<0.01*
Social function	8.59 (0.88)	0.00 (0.00)	<0.01*
School function	10.96 (0.98)	4.68 (0.47)	<0.01*

* $p < 0.05$

Factors affecting the quality of life of well-controlled epileptic children

In well-controlled epileptic children, the existence of other variables that may affect the quality of life should be considered. These additional variables were age at diagnosis, duration of suffering from epilepsy and type of therapy received. Long duration of suffering from epilepsy and age at diagnosis were proved to decrease the quality of life of well-controlled epileptic children.

DISCUSSION

Results of logistic regression analysis of the characteristics of the subjects showed that demographic factors were not risk factors for poor quality of life of epileptic children. This was consistent with Sherman *et al.*⁸ who reported that sociodemographic factors were not factors affecting the quality of life of epileptic children, while neurological and behavioral factors were more influential to the quality of life of epileptic children.

Results from this study indicated that well-controlled epileptic children had a lower quality of life than non epileptic children. This may occur because epileptic children underwent certain long-term treatment on a regular basis which would give effect to the functions in the domain of quality of life. The impact of long-term treatment was the disruption of school functions, because every month the child must be absent from school to conduct check up make in the clinic. School function indirectly indicated the cognitive function of children. Epileptic patients might have impaired cognitive function, which can be caused by the illness and side effects of treatment. Hermann *et al.*⁹ reported that the deterioration of cognitive function was associated with the early age at diagnosis and the duration of suffering from epilepsy, especially in conditions of tonic-clonic seizures, recurrent episodes of epilepticus status and increased exposure to the OAE.

The duration of suffering from epilepsy showed the length of time required to control seizures of these epileptic children. The more frequent seizures will cause damage to neuronal cells that lead to the decline of cognitive function. Diagnosis of epilepsy at early young age was closely related with poor quality of life. It was because age less than 5 years

is the golden period for brain growth and development of children, there fore when an interruption occurred during the period of epileptic seizures, it will automatically have an impact on the subsequent child development. A similar case was found in the research by Yong *et al.*¹⁰ and Wishwadewa *et al.*¹¹ Vendrame *et al.*¹² reported that duration of suffering from epilepsy and age at diagnosis were the best predictor of growth in the first year of life.

This research showed that most epileptic children only need one kind of epilepsy drugs to control their seizure. Absound and McShane reported that the seizure in approximately 70% of epileptic children can be controlled with single appropriate drug.¹³ Stevanovic stated that the longer duration of seizure absency, the better the quality of life of epileptic children.¹⁴

Side effects of valproic groups contributed to weight gain, endocrine changes, hepatotoxicity, tremors, and hair loss. Phenytoin groups have side effects such as cosmetic changes (gum hypertrophy), hipersensitivity reaction, while the phenobarbital (barbiturate) groups have side effect on behavioral and cognitive changes.¹⁵ Deterioration of cognitive function in epileptic patients who received phenobarbital group was poorer than those phenytoin and valproic groups. In addition, the consequences of this disease was the occurrence of negative views about epilepsy in children, and adults. This gave an explanation why the value of social function in the domain of quality of life showed extreme differences between both groups.

One of the weaknesses of this study was that the measurement of quality of life was only performed once. The quality of life is a very subjective therefore although it was attempted to be objective, reassessment may be needed to know the factors that really affecting the quality of life of individuals. The important thing which also can not be explored in this study was the level of knowledge of parents or caregivers about epilepsy which was mentioned as one of important factors affecting the level of quality of life of epileptic children.¹⁶

CONCLUSION

Quality of life of well-controlled epileptic children was lower than non epileptic children. Factors that affected quality of life of well-controlled

epileptic children were the duration of suffering from epilepsy and age at diagnosis of epilepsy. Further research on the quality of life must be conducted with a better design for example with periodic monitoring (cohort) to assess the quality of life and factors that influence. Continued research on the effects of stigma and anxiety of parents to the quality of life of well-controlled epileptic also needs to be performed.

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