Factors Affecting the Quality of Life in Children with Epilepsy

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Abstract:

Health-related quality of life (HRQOL) is considered as an important clinical outcome, especially in children with chronic illnesses. This predictive, descriptive study aimed at investigating the factors affecting health-related quality of life in children with epilepsy, including epilepsy severity, comorbidity, and family functioning. The sample, which consisted of 90 caregivers of children with epilepsy between the ages of 4 to 15 years, was recruited from the pediatric neurological out-patient clinic and in-patient wards at Prasat Neurological Institute, and Ramathibodi Hospital located in Bangkok, Thailand. Data were collected during June-August 2019. A set of questionnaires was used including demographic characteristics and medical record of illness data of children with epilepsy, the Chulalongkorn Family Inventory (CFI), and the Quality of Life in Childhood Epilepsy (QOLCE-16). Data analysis used descriptive statistics, Pearson's product-moment correlation coefficient, and multiple regression analysis. The findings revealed that epilepsy severity, comorbidity, and family functioning could jointly predict the overall QOLCE, and accounted for 28.40% of the variance in the overall quality of life of children with epilepsy. Results of this study would help nurses and healthcare professionals provide adequate support and further design the intervention to improve the quality of life among children with epilepsy.

Keywords: Predictive factors, Health-related quality of life, Childhood epilepsy

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ปัจจัยที่มีอิทธิพลต่อคุณภาพชีวิตเด็กโรคลมชัก

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บทคัดย่อ :

คุณภาพชีวิตเป็นสิ่งที่บ่งบอกถึงผลลัพธ์ทางการรักษาที่สำคัญทางคลินิกโดยเฉพาะอย่างยิ่งในผู้ป่วยเด็กโรคเรื้อรัง การวิจัยครั้งนี้มีวัตถุประสงค์เพื่อหาความสัมพันธ์เชิงทำนายปัจจัยที่มีอิทธิผลต่อคุณภาพชีวิตเด็กโรคลมชัก โดยปัจจัยคัดสรรได้แก่ ความรุนแรงของโรคลมชัก โรคร่วม และการทำหน้าที่ของครอบครัว กลุ่มตัวอย่างคือ ผู้ดูแลหลักของเด็กโรคลมชักช่วงอายุ 4-15 ปี ที่มารับการตรวจรักษาในคลินิกโรคระบบประสาทเด็กทั้งแผนกผู้ป่วยนอกและผู้ป่วยในสถาบันประสาทวิทยาและโรงพยาบาลรามาธิบดี จำนวน 90 ราย โดยเลือกตัวอย่างแบบเฉพาะเจาะจงตามคุณสมบัติที่กำหนด เก็บรวบรวมข้อมูลระหว่างเดือนมิถุนายน-สิงหาคม พ.ศ. 2562 เครื่องมือที่ใช้ในการเก็บข้อมูลประกอบด้วย แบบบันทึกข้อมูลส่วนบุคคล แบบบันทึกข้อมูลระดับความรุนแรงของโรคลมชัก แบบประเมินการปฏิบัติหน้าที่ของครอบครัว และแบบประเมินคุณภาพชีวิตผู้ป่วยเด็กโรคลมชัก วิเคราะห์ข้อมูลโดยใช้สถิติพรรณนา สัมประสิทธ์สหสัมพันธ์ของเพียร์สัน และการวิเคราะห์ความถดถอยเชิงพหุคูณ ผลการศึกษาพบว่าความรุนแรงของโรคลมชัก โรคร่วม และการทำหน้าที่ของครอบครัวสามารถร่วมกันทำนายคุณภาพชีวิตโดยรวมได้ร้อยละ 28.40 ผลการศึกษานี้จะเป็นประโยชน์สำหรับพยาบาลและบุคลากรทีมสุขภาพในการสนับสนุนการดูแลเด็กโรคลมชักอย่างเหมาะสมและออกแบบโปรแกรมเพื่อส่งเสริมคุณภาพชีวิตของผู้ป่วยเด็กโรคลมชักต่อไป

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Introduction

Epilepsy is one of the most common neurological condition in childhood. Approximately one-half of the patients with epilepsy experience their first seizure during childhood.[1] The incidence of epilepsy in children ranges from 41 to 87 per 100,000 persons a year worldwide. It has been reported consistently high in the first year of life and declines in adulthood.[2] Among the children in the US, the estimated lifetime prevalence of epilepsy is 1% or 10.20 per 1,000 persons; the current epilepsy occurrence is 6.30 per 1,000 persons.[3] In Thailand, a study has shown that the estimated prevalence of epilepsy is 7.20 per 1,000 persons of all ages. The highest two groups were found in children aged 5 to 9 years and adults aged 25 to 34 years, representing about 17 per 1,000 persons and 17.40 per 1,000 persons, respectively.[4]

Children with epilepsy are affected by the disease and long-term treatment; epilepsy deteriorates the child's life outcomes, such as having negative impacts on cognitive, behavioral, emotional, social, and overall health-related quality of life (HRQOL).[5] HRQOL is widely used to have a narrow focus on the effects of health, illness, and treatment on quality of life.[6] HRQOL in children with epilepsy covers many domains of functioning, such as the physical, psychological aspects, and their school performance and health status.[7] Previous studies reported that children with epilepsy were highly affected in terms of cognitive, physical, emotional, and social functioning, respectively.[8,9] Children with epilepsy have been reported to have lower overall HRQOL, compared to population norms, and experience poor long-term HRQOL associated with chronic health problems.[9,10]

Because childhood epilepsy is a chronic illness, the goal of management and care of children with epilepsy is to promote their HRQOL and enable them to live a normal life, free from medical and psychosocial complications as much as possible.[11] HRQOL routine measurements will provide useful information for healthcare professionals on patient problems as they can be used to manage medical and psychological problems in children with epilepsy.[12] The best way to promote children's HRQOL is to know the specific factors influencing their HRQOL. Factors affecting HRQOL in children with epilepsy need to be considered and further studied for therapeutic interventions.

The quality of life in children with epilepsy is associated with diverse factors. Most of the previous studies among children with epilepsy mainly focused on the disease and treatment. Many studies have been reported that a higher level of epilepsy severity brings about a decrease in overall HRQOL.[5,13,14] Children with epilepsy who exhibit co-morbidities have been reported a significantly low HRQOL.[13] This study selected some factors which reflect significant outcomes in evaluating the impact of the illness and its treatment on their life, such as epilepsy severity and comorbidity. Additionally, family functioning is one of the significant factors that can help children adjust to living with chronic disease. The study of Puka et al.[15] reported that the better family functioning, the higher HRQOL.

Based on the literature review, the studies on the quality of life of children with epilepsy in other countries are generally limited due to their focus on different cultures, healthcare systems, and the nature of care, which affect the results concerning the perceived quality of life. Recently, the study on the quality of life of children with epilepsy in Thailand is rarely found, and there are a limited number of studies on the specific factors affecting HRQOL among children with epilepsy. The results of this study would be helpful for a healthcare profession in providing adequate support, and further designing the intervention to improve quality of life among children with epilepsy.

Objectives of the study

1. To explore the level of quality of life of children with epilepsy.
2. To examine whether epilepsy severity, comorbidity, and family functioning can predict the quality of life of children with epilepsy.

Conceptual framework

The conceptual framework in this study is based on the theoretical model of health-related quality of life in youth with epilepsy (YWE) and a review of the literature in order to identify the determinant factors of HRQOL.[16] The model explored HRQOL and identified factors such as health status, personal factors, and environmental factors associated with health outcomes. Health status or level of impairment factors included epilepsy severity, duration of treatment, medications and adverse event of antiepileptic drugs (AEDs), and seizure control; personal factors included child's age, and comorbidity; and environmental factors involved community variable and family variable, such as family functioning. The selected factors of this study represent each level of factors affecting health-related quality of life in children and youth with epilepsy. These include epilepsy severity in terms of epilepsy variable/health status, comorbidity involving biomedical impairment, and family functioning considered as the closest environmental variable.

The severity of epilepsy is a specific characteristic of epilepsy and its treatment. The correlations between severity variables and children's HRQOL have been determined in meta-analysis studies among children with chronic illness.[16] The severity is associated with the physical health outcome and social activities of children with epilepsy. Several studies of children with epilepsy suggest that high severity of epilepsy is associated with decreased HRQOL.[5,13,14]

Comorbidity or biomedical impairments are commonly found in children with epilepsy and are associated with a decline in HRQOL.[16] Comorbidities contribute to the disease burden confronted by patients and their families. The co-existing disorders affect a patient's QOL and long-term outcomes. A previous study has found that the common comorbidities in children with epilepsy are cognitive problems, delayed development, learning disabilities, other neurological and psychological problems, physical disability, problems related to mental health, and behavior problems—all of which have been found to have the highest correlations with poor HRQOL.[9,17]

Family functioning is generally considered to be the exhibition of the relationships within the family.[18] The theoretical model of health-related quality of life in youth with epilepsy suggests that family functioning might have the potential to mediate the individual's HRQOL.[12] Family functioning is one of the closest environments to the children. Family functioning plays an important role in the day-to-day life of the children and has an essential role for individual physical and mental growth.[18] Children with epilepsy and their parents who have better family relationships and are able to perform family functioning well are positively linked to better HRQOL outcomes.[13,14,19]

Research hypothesis

Epilepsy severity, comorbidity, and family functioning can predict the quality of life in children with epilepsy.

Methods

The purposive sample of primary caregivers who lived with the children with epilepsy in the same household and have taken care of children for at least a period of six months, as well as accompanying the children during his/her visit to the hospital at the pediatric neurological department of two tertiary care medical centers for case follow-up was recruited based on the children's inclusion criteria as follows: 1) children aged 4 to 15 years who were diagnosed with epilepsy for at least six months; and 2) children who presented with or without any co-morbidities, including neurological, developmental or psychiatric, and medical disorders. Children with other non-neurological conditions, such as asthma, cancer, heart disease, kidney disease, or hematological disease, which require daily medication or treatment, and children having critical problems or those who need emergency help were excluded. The sample size was computed by using G*power program input medium effect of 0.15[20] that required at least 77 samples. A 15% sample size was added to prevent missing data or data collection errors. This study required approximately 90 caregivers in response to the questionnaire so as to achieve a power of .80 with an alpha of .05.

Instruments

1. Characteristics of children with epilepsy and their caregivers:

Demographic and medical history questionnaires for children with epilepsy were used to collect data, such as children's gender, age, duration of diagnosis, seizure type, seizure frequency, medication use, comorbidities, frequency of seizure, history of admission, and schooling status.

The demographic questionnaires for the caregivers were used to collect data, such as gender, age, marital status, health status, relationship with children, level of education, region of domicile, religion, occupation, income, daily number of hours spent providing care, level of care, total duration of care, and number of people under care.

2. Epilepsy severity scale: the epilepsy severity scale was developed by using the concept of seizure severity of Austin et al.[21] which determined the epilepsy score. According to seizure type, each type of seizure can be assigned to the different score from

1 to 3 (the most severe type was coded as the highest score) as follows: type 1 seizure included generalized tonic-clonic seizures or other types with loss of consciousness which were scored as 3; type 2 seizure included partial seizures or focal seizures with awareness which were scored as 2; and type 3 seizure included absences or typical absences which were scored as 1. The counting of seizure frequency was scored from 1 to 3 as follows: a score of 3 was provided in the case of monthly seizures with type 1 seizure; a score of 2 was given if the seizures happened less than once a month with type 1 seizure and/or had other types of seizure less than 15 times a month; and a score of 1 was given if the seizures occurred less than once a year for every type of seizure.[22] The presence of antiepileptic drug (AED) use was scored 0 to 3. If the child required no medication to control his or her seizures, this case was assigned a score of 0. The score of 1 was given for requiring monotherapy, a score of 2 was given for the presence of dual therapy, and in the case of polytherapy, the score was 3. The total scores for epilepsy severity were summed according to seizure type, seizure frequency, and medication regimen. The possible scores were 2 to 9. Scores 2 to 5 were considered as low epilepsy severity, and scores ≥ 6 were considered as high epilepsy severity.[21] Reliability was determined by Cronbach's alpha coefficients which were 0.76 for the overall severity score.

3. Chulalongkorn Family Inventory (CFI): the CFI reflects family functioning, and is provided in the Thai language. It was developed by Trangkasombat.[23] The CFI assesses the perception of family functioning, which is rating by family members. The CFI consists of 36 items with seven aspects; one scale reflecting a general functioning scale and six scales of family functioning based on the McMaster model. The items included (1) problem solving (5 items); (2) communication (5 items); (3) affective response (5 items); (4) affective involvement (5 items); (5) family role (4 items); (6) behavior control (4 items); and, (7) general functioning (8 items). There are 24 items reflecting a positive meaning, and being rated on a four-point Likert scale as follows: 1 = disagree; 2 = slightly agree; 3 = fairly agree; and 4 = strongly agree. Other 12 negative items (3, 6, 9, 12, 15, 18, 21, 24, 27, 30, 33, and 36) needed to transform the score as 4 = disagree; 3 = slightly agree; 2 = fairly agree; and 1 = strongly agree. The possible scores were 36 to 144 (higher scores reflected healthy functioning or better family functioning).[23] The psychometric properties of the Chulalongkorn Family Inventory was acceptable. This study found that the reliability (alpha) value was 0.87.

4. Quality of Life in Childhood Epilepsy (QOLCE-16): the QOLCE-16 is a disease-specific measurement of HRQOL in children with epilepsy, which is obtained by parent proxy-report. It was developed and revised for use as a short version instrument by Goodwin et al.[8] The QOLCE-16, being comprised of 16 items with an equal number of 4 items in 4 domains of functioning, includes the cognitive, emotional, social, and physical domains. Each item is rated on a five-point Likert scale as follows: 0 = very often; 1 = fairly often; 2 = sometimes; 3 = almost never; and 4 = never, and then the scores were transformed to a score with a minimum of 0 (low HRQOL) and a maximum of 100 (high

HRQOL). Items corresponding to each subscale were marked. The QOLCE-16 total score was the unweighted mean of the subscale scores. The possible scores were 0 to 100 (the higher scores reflected better quality of life). After the researcher was granted the permission from Dr. Shane W. Goodwin to use QOLCE-16 in this study, the back-translation process was used in order to create the QOLCE-16 in Thai version. Cronbach's alpha was used to determine the reliability of the subscales which were between 0.84-0.88 and 0.91 for the overall QOLCE-16.

Human subject protection

After the Ethical Review Committees for Research in Human Subjects, the Faculty of Medicine Ramathibodi Hospital, Mahidol University (No. MURA2019/438), and Prasat Neurological Institute (No. 036/2562) approved all of the clinical trials, data collections were initiated. The researcher informed the subjects about the objectives and methods of the study. After the subjects agreed to participate in the study, the researcher requested them to sign the consent form. The subjects were guaranteed that the data would be kept confidential and if they were uncomfortable, they could withdraw from the study at any time, and this study would not affect the child's treatment.

Data collection

Approval was obtained from the Research Ethics Committees on Human Rights from the Faculty of Medicine Ramathibodi Hospital, Mahidol University (No. MURA2019/438), and Prasat Neurological Institute (No. 036/2562). The researcher collaborated with the staff nurse to find the eligible participants by reviewing the patient's diagnosis and select the sample according to the inclusion criteria. Caregiver consent was obtained and questionnaires were administered. The participants completed questionnaires for approximately 15 minutes while waiting for the doctor. Data were collected during June-August, 2019.

Statistical analysis

The demographic and clinical data of children with epilepsy and their caregivers were analyzed by using descriptive statistics. Inferential statistic was used to test relationship between each of the independent variables and the dependent variables by using Pearson's Product Moment Correlation. Before performing the multiple regression analysis, five assumptions were tested, including normal distributions of all variables, linearity, homoscedasticity, autocorrelations, and multicollinearity. There was no violation of any of the assumption. All tests were using $p < 0.05$ as a statistically significant value.

Results

A total of 90 children diagnosed with epilepsy for at least six months were recruited from the neurological out-patient clinic and in-patient ward at Prasat Neurological Institute (n = 45), and the Faculty of Medicine Ramathibodi Hospital (n = 45). The gender distribution of the participants was roughly equal, with 51.10% male and 48.90% female. The subjects' ages ranged between 4.03 and 15 years old, with a mean age of 10.10 years (SD = 3.03). The majority of the subjects (31.10%) were 13 to 15 years old. The average duration of diagnosis was 6.02 years (SD = 3.07). Most (72.20%) of the children with epilepsy were able to attend school, of which 81.50% attended a regular school while 18.50% attended a special school. A low degree of school absence was found in the children with epilepsy, with just 21.50% being absent from school more than four times per month. Approximately 43.30% of children with epilepsy had no comorbidities. The majority of children with epilepsy presented 56.60% of co-morbidities. 27 children had one comorbidity, and 21 cases presented two comorbidities. Few children (5%) had three or more comorbidities. The demographic characteristics of children with epilepsy were presented in Table 1.

Table 1 Frequency, percentage, range, mean, and standard deviation of the demographic characteristics of children with epilepsy (N = 90)

Characteristics	**Frequency**	**Percentage**
Gender		
Male	46	51.10
Female	44	48.90
Age (years)		
4-6	18	20.00
7-9	20	22.20
10-12	24	26.70
13-15	28	31.10
(min = 4.03; max = 15; mean = 10.10; SD = 3.03)		
Type of co-morbidity		
Neurological comorbidities		22.50
Cerebral Palsy	10	12.50
Other neurologic disorders	8	10.00
Developmental or psychiatric comorbidities		61.30
Developmental Delay	13	16.20
Attention deficit/ hyperactivity disorder (ADHD)	7	8.70
Autism Spectrum Disorders (ASD)	4	5.00
Mental Retardation	2	2.50
Intellectual Disability	11	13.80
Behavior problems	5	6.30
Mood disorders/ aggressive	6	7.50
Social problems	1	1.30
Medical disorder		16.20
Metabolic disorders	9	11.20
Malnutrition	1	1.30
Sleep disorders	3	3.70

The clinical characteristics of children with epilepsy are presented in Table 2. The mean of epilepsy severity score was 6.60 (SD = 2). The majority of the participants had high severity, whereby they scored 6 or higher on the epilepsy severity score (65.50%). Most (58.90%) of the children with epilepsy were diagnosed with type 1, which refers to generalized tonic-clonic seizure or other types involving loss of consciousness or impaired awareness, such as atonic, complex partial, combined generalized and focal, and focal to bilateral tonic-clonic. Forty percent of children with epilepsy did not have a seizure for over one year. A small percentage of the participants (5.60%) did not depend on medication to control their seizures, although most of them (47.80%) took multiple drugs or more than two antiepileptic drugs (AEDs). Some of the children (25.60%) had adverse drug effects from AED use, including nausea, vomiting, weight loss, sleepiness, fatigued, drowsy, slow response or thinking, hyperactivity, and aggression.

Table 2 Frequency, percentage, range, mean, and standard deviation of clinical characteristics of children with epilepsy (N = 90)

Characteristics	Frequency	Percentage
Seizure type		
Type 1 Generalized tonic-clonic seizure or other types with loss of consciousness or impaired awareness	53	58.90
Type 2 Focal seizure with awareness	32	35.60
Type 3 Typical absences	5	5.50
Seizure frequency		
More than 12 times a year	33	36.70
Less than 12 times a year	21	23.30
No seizure more than 1 year	36	40.00
Antiepileptic drugs (AED)		
Absence of medication regimen	5	5.60
Monotherapy	24	26.70
Dual-therapy	18	20.00
Poly-therapy	43	47.80
Severity score (2-9)		
2-3	5	5.60
4-5	26	28.90
6-7	21	23.30
8-9	38	42.20
(min = 3; max = 9; mean = 6.60; SD = 2)		

A total of 90 primary caregivers were recruited in this study. A majority of the caregivers were female (86.70%), of which 73.30% were mothers and 8.90% were grandmothers. Most of the caregivers aged between 35 and 50 years, with a mean age of 41.03 years (SD = 7.09; range = 23-60). A total of 71% of the caregivers were married. Most of the caregivers were from the central region of Thailand (60%) and 96.70% were Buddhist. Most of them (41.10%) had completed secondary education, 25.60% had received a bachelor's degree, and 5.60% had a graduate degree or higher. The majority of the caregivers (77.80%) were employed. The caregivers' mean individual income was 18,962 baht per month (SD = 26,473; range = 0-200,000; median = 15,000). The average family income was 31,876 baht per month (SD = 34,248; range = 5,000 - 280,000; median = 20,000). Over 60% of the caregivers had an income equal to or lower than 15,000 baht per month, while 63% reported a family income more than 15,000 baht per month. Most of the families of children with epilepsy had an adequate income but with no savings (36.70%), but some of the caregivers (25.60%) had an insufficient income and were in debt. In terms of health status, the majority (72.20%) of the caregivers were healthy and 27.80% of the caregivers experienced chronic disease. The mean number of years spent caring was 9.3 years (SD = 3.08; range = 1-15). Most of the children with epilepsy (58.90%) required total care or help with all everyday activities from the caregivers. The majority (73.30%) of the caregivers had an assistant at home to help with caring for the children with epilepsy. On average, the caregivers provided care for the children with epilepsy for 14 hours per day (SD = 8; range = 2-24). A total of 24% of the caregivers were responsible for caring for more than two family members at a time. The analysis of mean score of family functioning was 115.81 (SD = 11.88), while the highest mean range of subscales included a problem solving, general functioning, roles, affective responsiveness, communication, affective involvement, and behavior control (3.45, 3.43, 3.22, 3.22, 3.21, 3.16, and 2.55, respectively).

Quality of life in childhood epilepsy (QOLCE) in overall and subscales illustrated that the mean score of overall QOLCE was 54.39 (SD = 21.19), while the highest mean score was emotional functioning (59.65), and cognitive functioning was the lowest score (47.08). Details are presented in Table 3.

Table 3 Mean, standard deviation, and range of quality of life in childhood epilepsy (N = 90)

Quality of life	Scores		
	Actual range	**Mean**	**SD**
Cognitive functioning	0-100	47.08	27.35
Emotional functioning	25-100	59.65	13.51
Social functioning	0-100	55.97	30.86
Physical functioning	0-100	54.86	29.44
Overall QOLCE	12.50-92.19	54.39	21.19

Pearson's correlations were used to analyze the relationship between each independent variable and dependent variable. The comorbidity and severity were negatively correlated with overall QOLCE at a low to moderate level ($r = -.21$, $p < .05$; $r = -.47$, $p < .01$, respectively). In contrast, family functioning was not found to be correlated with overall QOLCE ($r = .16$, $p > .05$).

Predictors of HRQOL

The data were analyzed by using multiple regression. The results of enter regression model showed that severity, comorbidity, and family functioning were co-predictors, accounting for 28.40% of the variance in overall QOLCE scores ($F_{(3,86)} = 11.356$, $p < .001$). Based on the findings, severity was the strongest predictor of the overall QOLCE (Beta = -.458, $p < .001$), followed by comorbidity (Beta = -.183, $p < .05$). However, family functioning was not a significant predictor of QOLCE (Beta = -.176, ns.) as demonstrated in Table 4.

Table 4 Enter multiple regression analysis of independent variables on overall QOL (N = 90)

Predictor Variables	B	SE	Beta	t	R^2	R^2 change	F change
Severity	-4.690	.937	-.458	-5.007**	.284	.284	11.356**
Comorbidity	-4.062	2.036	-.183	-1.996*			
Family-functioning	.313	.163	.176	1.923			

Constant = 52.696; Adjust R^2 =.259; over all F (3,86) = 11.356, *$p < .05$; **$p < .001$

Discussion

This predictive descriptive study reported the level of quality of life and identified the factors affecting health-related quality of life in children with epilepsy, including epilepsy severity, comorbidity, and family functioning. According to the study, the scores of quality of life in childhood epilepsy (QOLCE) illustrated that mean score of overall QOLCE was 54.39 (SD = 21.19). This was similar to previous studies that reported a moderate level of children's HRQOL.[9,19] When considering each aspect of quality of life, the results showed that cognitive functioning highly affected the child's health status. This result is consistent with previous studies, which reported that the lowest scores of children with epilepsy were cognitive functioning. It was found that cognition and concentration were most commonly affected due to epilepsy.[24] Cognitive functioning involved the problem in concentrating, remembering, and speaking. The level of cognitive functioning is related to the etiology of epilepsy and has a significant influence on a child's cognition and educational progress. The current study found that children with epilepsy presented a high score in emotional functioning. This result is consistent with Goodwin et al.,[8] which reported that children with epilepsy had emotional functioning better than physical functioning and cognitive functioning.

In the Thai culture, the nature of caregiver-child relationships is close in both younger children and adolescents. The close and caring interpersonal relationships that children with epilepsy have with their primary caregivers help them to develop well in their emotional aspect[26]. Some children with epilepsy experience limitations in social interactions and activities at school or society. The caregivers reported that epilepsy affected the child's social functioning at a moderate level. Furthermore, this study found different results from previous studies. Bompori et al.[17], for example, reported that children with epilepsy both in well-controlled and poorly-controlled seizure had the lowest score of peer and social environments. Many studies have reported that children with epilepsy have high social functioning.[8,9]

Epilepsy affects a child's social functioning at different levels, depending on his/her health status and social abilities. When considering physical functioning related to physical activities in a child's daily life, this study found that epilepsy affected the child's physical functioning at a moderate to high level, which is similar to the results from a previous study. According to Cianchetti et al.'s study[26], it was found that epilepsy highly reduced children and their family's extra-activities in daily life. Children who live with epilepsy might be limited to certain physical activities related to the onset of seizures. Overall, this study agrees with other studies that epilepsy impairs many aspects of HRQOL at a different degree.

According to the findings, epilepsy severity was negatively correlated with overall QOLCE. The higher level of epilepsy severity caused a decrease in overall QOL.[9,13] An explanation for this finding might be because the increase of the severity or the clinical presentation of uncontrolled seizures leads to polytherapy use, long-term treatment, and the presence of neurodevelopmental problems.[5,13,14] These cause a child to suffer more from the poor prognosis of the disease and the adverse effects of treatments that disrupt the child's development and functioning. Therefore, high epilepsy severity deteriorates overall HRQOL in children. Children with epilepsy demonstrated inconsistent physical development, psychosocial adjustment, all of which are associated with poorer overall HRQOL.

The findings showed that the number of comorbidities was negatively related to overall QOLCE. The higher number of comorbidities deteriorated HRQOL in children with epilepsy. The children with epilepsy in the present study presented an average of one comorbidity. Some of the children had more than one comorbidity, such as delayed development, intellectual disability, mental retardation, ADHD, ASD, CP, mood disorders or aggression, and behavioral problems. This study is similar to the previous studies[9,13] which reported that children with comorbidities, such as behavioral, cognitive, and neurological problems, have been found to be significantly associated with a decline in HRQOL.[9,17] This might be explained by the fact that children with epilepsy who exhibit comorbidities suffer from poor cognitive functioning, delayed development, behavioral problems, and poor social skills and social interaction. They therefore scored low in cognitive, social, and physical functioning, and had poor overall HRQOL.[19]

Regarding the findings that family functioning is not correlated with overall QOLCE, the previous findings were not consistent with this study, in which the primary caregivers scored higher in family functioning. This might be because most of the family caregivers perceived high family functioning. Even if their child's health status was low, the family members could manage the child's daily life and they rated their score at a high level of family functioning. When families can manage any problem well, it will positively affect the child's emotional domain. Caregivers who have a positive perception of changes in their family are able to perform their duties well and effectively manage the daily tasks of the child. This in turn leads to better family functioning and better patient and family well-being.[27] Family functioning might not have an effect on overall QOL, but was partially relevant to emotional functioning.

Conclusion

As for the relationship, the severity and comorbidity were negatively correlated to HRQOL. Severity, comorbidity and family functioning could co-predict overall quality of life in children with epilepsy. The strongest factor influencing quality of life in childhood epilepsy was epilepsy severity. Comorbidity influenced quality of life in childhood epilepsy at a low level. However, family functioning did not significantly predict the overall QOLCE. As a result, the research hypothesis was partially supported. The remaining predictors may have been explained by other factors which were not included in this study.

Implications for nursing practice

Overall findings from this study indicate that healthcare professionals should assess the child's QOL during routine visit in order to understand the child's quality of life and to ascertain the needs for satisfying their life, especially children with a high level of epilepsy severity and multiple comorbidities which may experience poor cognitive functioning and overall QOL. Healthcare team can also use the information to provide appropriate resources and to help a child receive medical care to control seizures, reduce epilepsy severity levels, minimize the effect of the disease and comorbidities in order to improve their quality of life.

Recommendations for future research

1. Future research needs to be further studied on environmental factors affecting quality of life, such as school ability, social skills, social interaction, self-worth, self-efficacy, family demographics, parenting style, economic burden, family support, social support, peer support, and school support since children with epilepsy are connected with their family members, teachers, peers, and siblings.

2. Although the QOLCE-16 parent proxy instrument has good psychometric properties with short completion time to measure HRQOL in children

with epilepsy, there is a need to measure child's self-report to capture HRQOL.

3. Additionally, long-term studies should be conducted in order to compare quality of life through assessing at each follow-up visit periodically because QOL might change due to health status and treatment.

Limitation of the study

The study findings must be interpreted cautiously with some limitations. First, this study recruited children from a wide age range and the quality of life might be expressed differently between the young children and adolescents. Second, the evaluation of quality of life by a caregiver or parent proxy might be limited to the individual perceptions of health status and functioning among adolescents. Lastly, when considering the QOLCE questionnaire, it was limited to scoring for children with a bedridden status or severe delayed development.

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