Quality of Life in Adolescent Absence Epilepsy at Queen Sirikit National Institute of Child Health

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Objective: *To compare the QoL between adolescents with absence epilepsy and the other types of epilepsies.*
Material and Method: *A prospective cohort study was conducted in adolescents aged 10-18 years that have been diagnosed with epilepsy at QSNICH between 2000 and 2012. The QoL was assessed using the QoLIE-AD-48, Thai version.*
Results: *Seventy-three adolescents were included in this study, of which 27 had absence epilepsy. The mean total QoLIE-AD-48 score was 63.94 (17.14). The absence group had a mean score of 74.45 (9.83), while the non-absence group had a score of 57.78 (17.57), p-value <0.001.*
Conclusion: *The QoL of adolescents with inactive absence epilepsy was significantly higher than those suffering with other types of epilepsy. The QoL in this study was similar to prior studies.*

Keywords: *Adolescent, Absence, Epilepsy, Quality of life*

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Epilepsy is a chronic illness requiring long-term treatments. It greatly affects the patients and their family's well-being, especially in adolescents. There are several indications to suggest that adolescents with epilepsy have higher prevalence of behavioral problems, impaired cognitive function, and reduced Quality of Life (QoL)[1-8].

The adolescence period is the transitional stage from childhood to adulthood. This period is critical for physical and mental development, including physical maturation, behavioral, and self-independence[1,2,9-11]. Adolescents might be unable to control their seizure attacks. This abnormal behavior leads to stigmatization from others, impeded independence and effect on peer relationships, self-esteem, mood and cognition.

According to the literature, patients with absence seizures suffer more and have an increased risk for poor health-related QoL[4,9]. Absence epilepsy is considered benign idiopathic epilepsy with easy treatment and good prognosis[1,4,9,10].

The purpose of present study is to investigate epilepsy in adolescents and how it affects QoL. Furthermore, the authors would like to compare the QoL between patients with absence and non-absence epilepsy, through the use of the Thai version of QoLIE-AD-48[11].

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Material and Method

Study subjects

Seventy-three adolescents were enrolled at the Neurology Outpatient Clinic of Queen Sirikit National Institute of Child Health (QSNICH). The subjects were interviewed at the Neurology Clinic although some cases were sent questionnaires via mail during 1 January 2012 to 31 December 2012. All participants were fully informed and consent obtained with approval from QSNICH Ethic Committee.

The eligibility criteria included epileptic patients aged 10 to 18 years, who received treatment, and follow-up at least every 6 months from 1 January 2000 until 1 December 2012. Individuals were excluded if they had surgery for their epilepsy in the past year, used concomitant medication affecting the central nervous system, or had another progressive neurologic or psychiatric illness.

Demographic data

For the clinical characteristics of the participants, we conducted a prospective cross-sectional study from 1 January 2000 to 31 December 2012, by collecting data from medical records. Data

collection was also done through questionnaires. The data collection is including demographic data and clinical characteristics. EEG results were reviewed by two pediatric neurologists. Informed consent was obtained from the parents prior to participating in the study.

QoLIE-AD-48

The QoLIE-AD-48 questionnaire was used to determine the QoL of adolescents with epilepsy[10,11]. The questionnaire includes eight different domains, that consist of the following 48 items: Epilepsy Impact (12 items), Memory/Concentration (10 items), Physical Func-tioning (5 items), Stigma (6 items), Social Support (4 items), School Behavior (4 items), Attitudes Towards Epilepsy (4 items) and Health Perceptions (3 items) which the high scores reflect to good QoL.

Statistical analysis

Regarding data storage and analysis, the authors used SPSS software version 16.0. Independent variables included in the analysis were clinical characteristics (age, sex), seizure variables, type of seizure, and age at onset of seizures. Dependent variables were adolescents' total QoLIE-AD-48 scores and the eight sub-scores. The results were calculated as frequencies, mean, and standard deviations. The comparison of groups was conducted by the student t-test, analysis of variance (type of seizure and seizure-free). Significance was computed at $p<0.05$. A regression analysis was performed for the significant variables.

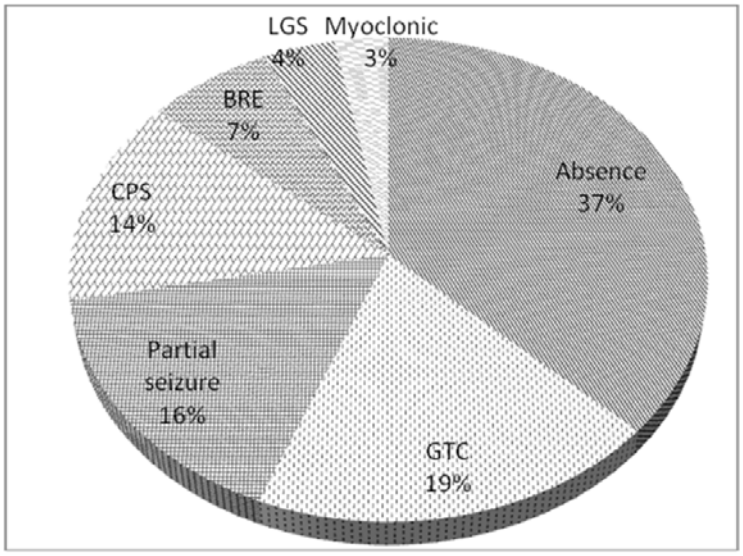
Results

Demographics, seizures, and medication data

Seventy-three adolescents, aged 10 to 18 years old, were enrolled at the Neurology Outpatient clinic of QSNICH. Demographic data showed that 37 participants were girls (51%) and 36 were boys (49%). Twenty-seven participants had absence epilepsy. The male to female ratio is 1:1. The absence epileptic to non-absence epileptic ratio was 0.9:1.

The mean age of seizure onset was 4.9 years in the absence group, and 8.6 years in the non-absence group. The majority of the patients had absence epilepsy and the others had various types of the seizures (Fig. 1). The three most common types were complex partial seizure (CPS), focal seizure and generalized tonic clonic (GTC).

The severity of seizures was described on the basis of the International League Against Epilepsy (ILAE) classification system[12]. Twenty-five (92.6%) of the participants with absence epilepsy did not experience a seizure in the previous year, better than twenty-three (50.0%) of the non-absence group did (Table 1). In addition, approximately 80% of the absence



GTC = Generalized tonic clonic; CPS = Complex pontial seizure; BRE = Benign relandic epilepsy; LGS = Lennox gastaut syndrome

Fig. 1 Types of seizures.

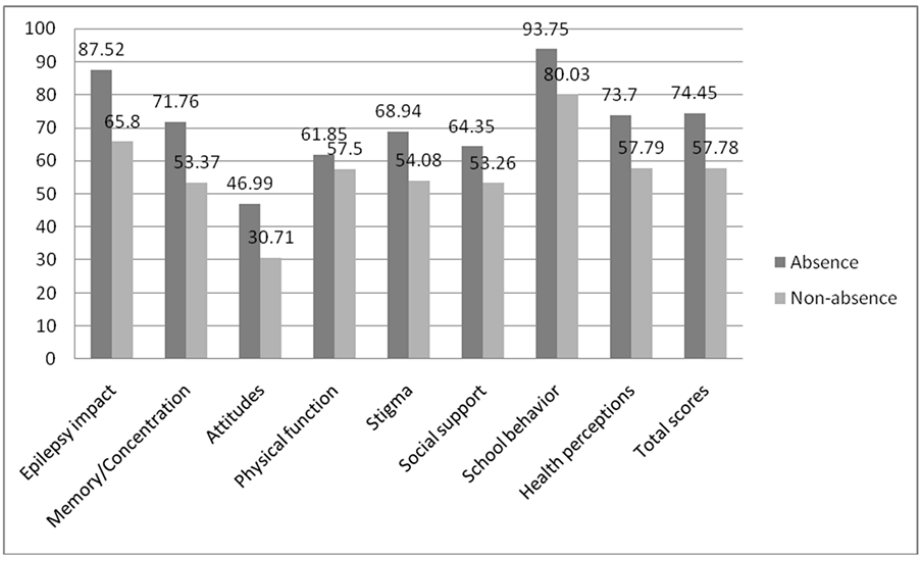
Table 1. Illustration of the categorization of seizure severity based on ILAE classification system, 2001 (HG Wieser, 2001[12])

Characteristics[A]	Absence (n = 27)	Non-absence (n = 46)
Class 1: complete seizure free, no aura	25 (92.6%)	23 (50%)
Class 2: only aura, no other seizure	0 (0%)	2 (4.3%)
Class 3: 1-3 seizure day/year ± auras	1 (3.7%)	8 (17.4%)
Class 4: seizure days/year to 50% reduction of baseline seizure days ± auras	1 (3.7%)	5 (10.9%)
Class 5: <50% reduction of baseline seizure days ± auras	0 (0%)	8 (17.4%)
Class 6: >100% increase of baseline seizure days ± auras	0 (0%)	0 (0%)

[A] characteristics of the seizure experienced in the past 12 months

Table 2. Comparison of number of AED therapy between absence and non-absence group ($p \leq 0.001$)

AED therapy	Absence (n = 27)	Non-absence (n = 46)
None	22 (81.5%)	6 (13.0%)
Monotherapy	3 (11.1%)	21 (45.7%)
Di- or poly-therapy	2 (7.4%)	19 (41.3%)



The difference between the domains are statistically significant, $p<0.01$

Fig. 2 Mean QoLIE-AD-48 in absence and non-absence participants at QSNICH.

group was seizure-free for more than 2 years and did not use medication (Table 2) whereas 13% of the non-absence group was free from seizures.

QoLIE-AD-48 scores

The mean (SD) total score of QoLIE-AD-48 of the absence and non-absence group were 74.45 (9.83) and 57.78 (17.57), respectively (Fig. 2). All of the subscales were significantly higher in the absence group, except for the physical function and social support domains. All of the domains of QoL were higher than 50% in the absence group, excluding for the attitude towards epilepsy.

Reliability analysis

The reliability of the data is presented in Table

3. Internalized consistency was assessed with Cronbach's alpha coefficient. The results showed that our measurements had satisfactory internal validity all of which are above the conventional standard of ≥0.8 (0.80-0.93), except in health perceptions and physical function domains.

Discussion

In the present study, the authors assessed the demographic data and QoL of adolescents with absence and non-absence epilepsy. The gender distribution of two groups was not different, but difference was found in the age of onset, type of epilepsy, severity of seizures and time to seizure-free.

Table 3. The reliability of QoLIE-AD-48 subscales[a]

Items	Cronbach's alpha coefficient[b]
Epilepsy impact	0.93
Memory-concentration	0.92
Attitudes	0.80
Physical function	0.79
Stigma	0.85
Social support	0.83
School behavior	0.81
Health perceptions	0.63
Total score	0.95

[a] All subscale scores were linearly transformed to range from 0 to 100 points, with higher values representing better functioning.

[b] a≥0.9 = Excellent (High-Stakes testing), 0.8≤a<0.9 Good (Low-Stakes testing), 0.7≤a<0.8 Acceptable (Surveys), 0.6≤ a<0.7 Questionable

The age of onset, severity, and time to seizure-free in the absence group did not seem to affect the QoL. Participants in this group had a higher QoL because absence epilepsy is easy to control with monotherapy and has a higher success rate of seizure remission. However, Kaindl[13] reported that the age of onset is a complex confounding variable because onset prior to the age of 3-4 years is more likely to be associated with mental retardation, difficult to control seizures, type of epilepsy, and AED poly-therapy.

From these results, we can predict that the QoL of inactive absence epilepsy is better than non-absence epilepsy in all subscales by using QoLIE-AD-48. The QoL in this study was scored above 50, which reflects good QoL. The highest score was the school behavioral domain, followed by epilepsy impact, health perception but the attitude towards epilepsy is the lowest score. The above mentioned represents the adolescent, active seizure, were more likely to perceive a negative impact on their life and more negative attitudes toward epilepsy.

Prior studies in different countries[10,14-18] have evaluated the QoL of adolescents with epilepsy in similar age groups, sex, and age of onset by using the QoLIE-AD-48. Results from those studies showed that the average of the total scores was consistent with our study, shown in Table 4. Table 4 shows the comparison of QoL scores across different domains and countries. The highest score observed in this study is school behavior, which is similar with the prior studies. On the other hand, other studies showed that the attitude towards epilepsy scores was the lowest, which reflects negative perception. Therefore, it is recommended that we educate them to learn to live with this lifestyle.

Table 4. Comparison between QoL scores across different domains and countries

Items mean (SD)	Overall 2013 (n = 73)	US & Canada 1999[10] (n = 197)	Spain, 2004[14] (n = 66)	Nigeria, 2006[15] (n = 86)	Brazil, 2008[16] (n = 93)	China, 2010[17] (n = 47)	Slovakia, 2012[18] (n = 74)
Epilepsy impact	73.9 (23.4)	70.6 (26.9)	92.3 (13.8)	67.3 (7.8)	74.4 (18.0)	70.1 (22.5)	83.6 (13.4)
Memory-concentration	60.2 (22.1)	67.6 (22.4)	76.0 (19.7)	66.8 (8.8)	69.6 (18.3)	66.1 (19.8)	75.9 (14.8)
Attitudes	36.7 (21.2)	39.8 (22.8)	35.6 (17.1)	32.2 (6.4)	39.3 (20.0)	69.2 (22.5)	33.9 (21.3)
Physical function	59.1 (27.3)	63.6 (30.6)	94.8 (13.1)	59.6 (8.0)	76.1 (22.0)	67.1 (24.7)	89.6 (12.6)
Stigma	59.6 (23.5)	71.3 (22.0)	86.0 (20.1)	66.0 (11.3)	74.7 (16.0)	62.9 (26.4)	77.8 (16.8)
Social support	57.4 (25.2)	72.4 (24.4)	81.0 (22.3)	89.5 (8.3)	81.5 (21.9)	33.2 (26.1)	88.2 (18.3)
School behavior	85.1 (21.3)	90.3 (15.4)	92.0 (18.0)	86.6 (7.4)	83.3 (15.2)	86.3 (9.8)	90.3 (15.4)
Health perceptions	63.7 (19.0)	65.8 (19.1)	66.9 (14.4)	66.5 (10.7)	69.2 (17.4)	52.8 (18.3)	81.7 (19.1)
Total score	63.9 (17.1)	67.7 (17.3)	80.3 (10.7)	66.8 (5.0)	69.9 (17.4)	65.6 (14.1)	75.2 (19.3)

In Thailand and other countries, adolescents with epilepsy have been a target of prejudicial behavior; prevailing cultural attributes stigmatize people with epilepsy. Results from several studies showed that the attitude towards epilepsy scores were less than 50%, which suggests that opinion held towards adolescence epilepsy is negative. Hereby, we recognize the importance of creating values for our patients and lead them to develop goals and reprocess maintenance.

Clinical implications

Further studies of the pediatric epilepsy could be realized of their attitude. The authors would like to encourage people to understand the knowledge of epilepsy, public education campaigns and together with the psychosocial support to improved their QoL especially the adolescent period.

Limitations

The authors only included inactive absence epilepsy in the present study, which may affect the QoL results, because this type of epilepsy has better prognosis when compared to the other types. Furthermore, this study did not evaluate the QoL in other types of seizures such as idiopathic, structural or cryptogenic. Future studies on these types of seizures are highly warranted.

Conclusion

The QoL of adolescents with inactive absence epilepsy is significantly better than other types of seizures. The QoL in this study was similar to prior studies, while the domain score of attitude towards epilepsy is lower than other domains. This may be reflective of their negative internalization.

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Potential conflicts of interest

None.

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การศึกษาคุณภาพชีวิตของผู้ป่วยโรคลมชักชนิดเหม่อในกลุ่มผู้ป่วยวัยรุ่นของสถาบันสุขภาพเด็กแห่งชาติมหาราชินี

ศิโรรัตน์ สุวรรณโชติ, ธนินทร์ เวชชาภินันท์, สมจิต ศรีอุดมขจร

วัตถุประสงค์: *เปรียบเทียบคุณภาพชีวิตของผู้ป่วยระหว่างโรคลมชักชนิดเหม่อและชนิดอื่นในวัยรุ่น*

วัสดุและวิธีการ: *การเก็บข้อมูลการศึกษาแบบไปข้างหน้า ในกลุ่มวัยรุ่นที่ได้รับการวินิจฉัยว่าเป็นโรคลมชักช่วงอายุ 10-18 ปี ของสถาบันสุขภาพเด็กแห่งชาติมหาราชินีตั้งแต่ปี พ.ศ. 2543 ถึง พ.ศ. 2555 โดยใช้แบบสอบถามคุณภาพชีวิต QOLIE-AD 48 ที่แปลเป็นภาษาไทย*

ผลการศึกษา: *ผู้เข้าร่วมวิจัยจำนวน 73 ราย โดยเป็นผู้ป่วยโรคลมชักชนิดเหม่อ 27 ราย พบว่าคะแนนเฉลี่ยของคุณภาพชีวิตของผู้เข้าร่วมวิจัยทั้งหมดเป็น 63.94 (17.14) กลุ่มที่เป็นโรคลมชักชนิดเหม่อ 74.45 (9.83) และโรคลมชักชนิดอื่น 57.78 (17.57) ซึ่งแตกต่างอย่างมีนัยสำคัญทางสถิติ ($p<0.001$)*

สรุป: *คุณภาพชีวิตของผู้ป่วยโรคลมชักชนิดเหม่อดีกว่าโรคลมชักชนิดอื่นอย่างมีนัยสำคัญ*