Social Outcome and Quality of Life after Epilepsy Surgery in Hippocampal Sclerosis

Peerasin Towachiraporn, M.D.[*]
Krishnapundha Bunyaratavej, M.D.[*]
Chusak Limotai, MD., M.Sc.[†]
[*]Neurosurgery Surgery Unit, Department of Surgery, Faculty of Medicine, Chulalongkorn University, Bangkok, Thailand.
[†]Department of Medicine, Faculty of Medicine, Chulalongkorn University, Bangkok, Thailand.

Abstract

Background: Quality of life is worse in patients with epilepsy as compared to that of general population. Although seizure freedom is the ultimate treatment goal in epilepsy surgery, patient's expectations and improvement in quality of life may also include other social aspects such as education, employment, income, driving and social relationships.

Objective: To investigated social outcomes, quality of life, social factors influencing quality of life, presurgical patient's expectation and patient's satisfaction after temporal lobe epilepsy (TLE) surgery.

Methods: Seventy-three patients with medically refractory hippocampal sclerosis (HS) who underwent epilepsy surgery between January 2014 and December 2019 at King Chulalongkorn Memorial Hospital (KCMH) were evaluated. The socioeconomic data was collected from the subjects and their caregivers by a questionnaire-interview. All patients had completed at least 2-year postoperative follow-up.

Results: There were 27 males (37%) and 46 females (63%) with mean age of 35.82 ± 10.14 years at the time of surgery. Seventy-one (97%) patients underwent standard anterior temporal lobectomy. Sixty-six (90.41%) patients reported excellent seizure outcome (ILAE Class I). For social outcome, there were significant changes in driving status (45.21 vs 60.27%, p = 0.008) but there was no significant change in other aspects (education, employment, income, marital status) after surgery. All patients reported excellent postoperative quality of life. The factors which were associated with better quality of life following surgery were employment (p = 0.036) and ability to drive (p = 0.006). Sixty-four (88%) patients cited seizure control as their main expectation. Sixty-seven (91.78%) patients were satisfied with surgery and would suggest other patients to pursue similar surgical treatment.

Conclusions: Surgery for medically refractory temporal lobe epilepsy improves social outcomes in driving aspect. Gaining employment and ability to drive after surgery are important factors influencing better quality of life. Vocational and driving rehabilitation program should be included in comprehensive epilepsy treatment program in order to enhance postoperative quality of life in TLE patients.

Keywords: Temporal lobe epilepsy, Hippocampal sclerosis, Epilepsy surgery, Social outcome, Quality of life

บทคัดย่อ

พีรศิลป์ โตวชิราภรณ์, พบ.[*], กฤษณพันธ์ บุณยะรัตเวช, พบ., วว. ประสาทศัลยศาสตร์[*], ชูศักดิ์ ลิโมทัย, พบ., วว. ประสาทวิทยา[†]

[*]หน่วยประสาทศัลยศาสตร์ ภาควิชาศัลยศาสตร์ คณะแพทยศาสตร์ จุฬาลงกรณ์มหาวิทยาลัย

[†]สาขาประสาทวิทยา ภาควิชาอายุรศาสตร์ คณะแพทยศาสตร์ จุฬาลงกรณ์มหาวิทยาลัย

ความเป็นมา: ผู้ป่วยโรคลมชักมีคุณภาพชีวิตต่ำกว่าประชากรทั่วไป แม้ว่าเป้าหมายหลักของการรักษาผู้ป่วยโรคลมชักคือการทำให้อาการชักลดลงหรือหายจากอาการชัก ความคาดหวังของผู้ป่วยและปัจจัยที่ส่งผลต่อคุณภาพชีวิตอาจมีมากกว่าการควบคุมอาการชักได้ แต่ยังรวมถึงปัจจัยอื่นๆ ทางสังคม เช่น การศึกษา การมีอาชีพ มีรายได้ ความสามารถในการขับขี่ และ ความสัมพันธ์ทางสังคม เป็นต้น

วัตถุประสงค์: เพื่อศึกษาผลการรักษาในด้านสังคม คุณภาพชีวิต ปัจจัยทางสังคมที่มีผลต่อคุณภาพชีวิต ความคาดหวังและความพึงพอใจของผู้ป่วยโรคลมชักที่ได้รับการผ่าตัด

วิธีการศึกษา: ผู้ป่วยโรคลมชักทั้งหมด 73 คน ที่ได้รับการวินิจฉัยเป็นโรคฮิปโปแคมปัสฝ่อที่ไม่ตอบสนองต่อการรักษาด้วยยา และได้รับการผ่าตัดตั้งแต่ พ.ศ 2557 – 2562 ณ โรงพยาบาลจุฬาลงกรณ์ ผู้ป่วยทั้งหมดได้รับการตรวจติดตามอย่างน้อย 2 ปีหลังผ่าตัด เก็บข้อมูลโดยใช้วิธีสัมภาษณ์ร่วมกับแบบสอบถาม

ผลการศึกษา: ผู้ป่วยทั้งหมด 73 คน เป็นเพศชาย 27 คน (37%) และเพศหญิง 46 คน (63%) อายุเฉลี่ยของผู้ป่วย ณ ช่วงที่ได้รับการผ่าตัดคือ 35.82 ± 10.14 ปี ผู้ป่วยร้อยละ 97 ได้รับการผ่าตัด standard anterior temporal lobectomy ผลการส่งตรวจทางพยาธิวิทยาเป็น hippocampal sclerosis (HS) ทั้งหมด ผู้ป่วยร้อยละ 90.41 มีผลการรักษาควบคุมอาการชักได้ดี (ILAE Class I)

ผลการรักษาพบว่าจำนวนผู้ป่วยที่สามารถขับขี่ยาพาหนะได้มีมากขึ้นอย่างมีนัยยะสำคัญทางสถิติ (45.21 vs 60.27%, p =0.008) แต่ในด้านอื่นๆ ไม่ว่าจะเป็นระดับการศึกษา อาชีพ รายได้ สถานะสมรส ไม่มีความแตกต่างกันเมื่อเทียบก่อนและหลังผ่าตัด คุณภาพชีวิตโดยรวมของผู้ป่วยในการศึกษาอยู่ในเกณฑ์ดีมาก โดยปัจจัยที่มีผลต่อคุณภาพชีวิตที่ดีคือ การมีอาชีพ (p=0.036) และมีความสามารถในการขับขี่ยานพาหนะ (p=0.006) ร้อยละ 88 ของผู้ป่วยต้องการหายจากอาการชักหลังจากได้รับการผ่าตัด โดยรวมผู้ป่วยส่วนใหญ่พึงพอใจต่อการรักษาโดยการผ่าตัดและจะแนะนำการรักษาโดยการผ่าตัดให้แก่ผู้อื่นที่เป็นโรคลมชักต่อไป

สรุป: การผ่าตัดรักษาผู้ป่วยโรคลมชักที่ไม่ตอบสนองต่อการรักษาด้วยยาช่วยเพิ่มความสามารถในการขับขี่ยานพาหนะกับผู้ป่วย และปัจจัยที่ส่งผลต่อผลต่อคุณภาพชีวิตที่ดีคือ การมีอาชีพและมีความสามารถในการขับขี่ยานพาหนะ ดังนั้นการการฟื้นฟูสมรรถภาพด้านอาชีพและการขับขี่มีความสำคัญและควรรวมไว้อยู่ในระบบการรักษาผู้ป่วยโรคลมชักเพื่อให้การรักษาเป็นแบบองค์รวมมากขึ้นและช่วยเพิ่มคุณภาพชีวิตให้แก่ผู้ป่วย

คำสำคัญ: โรคลมชัก, โรคฮิปโปแคมปัสฝ่อ, การผ่าตัดรักษาผู้ป่วยโรคลมชัก, ผลการรักษาในด้านสังคม, คุณภาพชีวิต

Introduction

Temporal lobe epilepsy (TLE) is the most common form of focal epilepsy[1]. Hippocampal sclerosis (HS) is a common pathology encountered in TLE[2]. Quality of life is generally lower in patients with epilepsy as compared to that of general population[3]. The randomized controlled trial showed superiority of surgery over medical therapy in terms of seizure control, quality of life, and rates of employment among patients with medical refractory TLE[4,5]. Seizure freedom was 40–80% after TLE surgery in long term follow up (5–10 years)[6]. Although seizure freedom is the ultimate treatment goal in epi-

lepsy surgery, patient's expectations may go beyond seizure control. Epilepsy patients have lower rates of employment, lower socioeconomic status, and lower income compared to the general population[7-9]. Thus, their expectations may also include improvement of other aspects such as education, employment, income, driving, and social relationships. Educational outcomes may be related to the location of surgery, duration of epilepsy prior to surgery, and age at onset of seizures[10]. Memory impairment is the most common cognitive adverse effect of TLE surgery and may have a negative impact on a patient's educational capability especially after dominant temporal lobe resections[11]. For employment outcomes after epilepsy surgery, the data are inconsistent. Some studies showed no change in employment status[12-14], while others reported increased employment[15,16]. The factors predicting favorable employment outcomes include younger age, shorter duration of epilepsy, pre-existing employment, and favorable seizure outcome[10,12,13]. There are only a few studies exploring changes in income after epilepsy surgery. One study showed an increase in average annual incomes per capita of 45.08% after surgery[15], while another study did not show a significant increase of financial independence after surgery (72% vs 80%, $p > 0.05$). However, the patients who had surgery were financially better as compared to the medically treated patients (80% vs 52%)[17]. The ability to drive is another important aspect with a significant impact on daily living including employment, socializing, and health care visits[10,12]. Obstacles for driving in post-surgery TLE patient include visual field defect, persistent seizure after surgery, and older age at the time of surgery[10,18]. People with epilepsy have lower marriage rates, higher social isolation rates. They are less likely to live independently and less likely to have children than the general population[19]. After surgery, TLE patients had higher marriage rates than those with extratemporal lobe epilepsy and seizure-free patients had higher marriage rates than those with recurrent seizures[20]. Recently, there are a few studies investigating social outcome and quality of life after epilepsy surgery in TLE patients. To the best of authors' knowledge, this data is lacking in Thailand. Therefore, this study is aimed to evaluate the social outcome, quality of life and patient's satisfaction after epilepsy surgery in Thai TLE patients.

Materials and Methods

This is a descriptive, cross sectional study reviewing database of the Chulalongkorn Comprehensive Epilepsy Center of Excellence (CCEC), King Chulalongkorn Memorial Hospital (KCMH), Thai Red Cross Society. This study involving human participants was approved by the Institutional Review Board (IRB No. 861/63 and COA No. 060/2021)

Patients

This study recruited 73 patients who were over 18 years old with medically refractory hippocampal sclerosis and underwent epilepsy surgery between January 2014 and December 2019. All patients had at least 2 years of post-surgery follow-up. Patients who were unable to complete the questionnaires were excluded.

Data collection

The demographic data were retrieved and collected from the database. Socioeconomic data was obtained from the subjects and their caregivers by the questionnaire-interview at CCEC or by a telephone interview during COVID-19 pandemic situation.

The questionnaires consist of 3 parts. Firstly, socioeconomic status includes pre- and post-operative data of educational level, employment status, incomes,

marital status, and driving. Secondly, the quality of life as measured by EQ-5D-5L (Thai version for Thailand). Lastly, presurgical expectations and postsurgical satisfaction as evaluated by the subjects.

Outcome measures

The occupation was classified by using modified kuppuswamy's scale[21] into professional, semi-professional, arithmetic skill job, skilled worker, semi-skilled worker, unskilled worker, and unemployed. Change in employment status after surgery was categorized into improved, worsened, or unchanged.

EQ-5D-5L consists of two parts. First part of the descriptive system comprises five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension is graded into 5 levels: no problems, slight problems, moderate problems, severe problems, and extreme problems. This utility score of this part was calculated by Thai population-based preference scores[22]. Second part is the EQ VAS which is the patient's self-rated health report on a vertical visual analogue scale (0-100).

Statistical analysis

Descriptive categorical data were presented as frequency and percentage, whereas continuous data the central tendency with associated data dispersion was reported as mean with standard deviation (SD) or median with interquartile range (IQR) depending on distribution normality of the data. McNemar's test was used to test association of the social outcomes pre- versus post-operative period. For a test of the difference of the visual analog scale score of the quality-of-life assessment at postoperative period between positive and negative social outcomes, unpaired t-test was employed. To assess the factors influencing better quality of life at postoperative period, univariate and multivariate linear regression model, adjusted with all other social outcomes, was used. Level of statistical significance was set to < 0.05 in all analyses.

Result

Baseline characteristics

There were 27 (37%) males and 46 (63%) females with a mean age of 35.82 ± 10.14 years at the time of surgery. The mean age at onset of epilepsy was 12.64 ± 6.95 years and the mean duration of epilepsy prior to surgery was 23.26 ± 10.16 years. The median of monthly seizure frequency was 30 (IQR = 50). A mean post-surgery follow-up duration was 4.38 ± 1.72 (range 1.54 – 7.73) years. At the time of the last follow up, 66 (90.41%) patients reported seizure freedom (ILAE Class I). Details of clinical data are presented in Table 1.

Social outcome and quality of life

Education level

There was only 1 patient with higher educational level after the surgery. Overall, there was no significant difference of educational level between pre- and post-operative period. Details of education level before and after surgery are shown in Table 2.

Employment outcome

Prior to surgery, 55 (75.34%) patients were employed. After surgery, 5 (6.8%) additional patients were employed but the difference of pre- and post-operative employment did not reach statistical significance (75.34% vs 82.19%, $P = 0.059$). Details of employment status are shown in Table 2.

In both pre- and post-surgery period, over 50% of patients were in the semi- skilled worker (e.g. farmer

Table 1 Clinical data of patients (N =73)

Characteristics	Results
History of febrile seizure, n (%)	29 (39.73)
History of CNS infection, n (%)	5 (6.85)
History of head injury, n (%)	13 (17.81)
History of status epilepticus, n (%)	8 (11.11)
Intellectual disability, n (%)	0 (0)
Abnormal neurological signs, n (%)	5 (6.94)
Psychiatric comorbidity, n (%)	4 (5.48)
Family history of epilepsy, n (%)	17 (23.29)
Type of surgery, n (%)	
Standard anterior temporal lobectomy	71 (97.26)
Selective amygdalo-hippocampectomy	1 (1.37)
Lesionectomy	1 (1.37)
Pathological findings, n (%)	
HS only	30 (41.10)
HS with gliosis	42 (57.54)
HS with benign-tumor	1 (1.37)

and factory worker) and unskilled worker (e.g. merchant, housekeeper) group. After surgery, the number of patient who were in skilled worker group or above had increased from 36 (49.32%) to 39 (53.42%). However, there is no significant change in class of occupation in after surgery. The class of occupations are detailed in Table 2.

Income

Majority of the patients had average monthly income ranging from 5,000 to 30,000 baht. The number of patients with income has increased from 48 (65.8%) to 52 (71.2%) postoperatively but that did not reach statistically significance (p = 0.206). Details of patient's income are shown in Table 2.

Other aspects

There was a significant increase of driving status after surgery (45.21 vs 60.27%, p = 0.008) but there was no significant change of marital or parental status between pre- and post- operative period. Details are shown in Table 2.

Quality of life

After surgery at the time of the questionnaire-interview, median of EQ-5D-5L score of all five dimensions (mobility, self-care, usual activities, pain/discomfort and anxiety/depression) were 1 and mean

Table 2 Social outcomes

Social outcomes	Pre-surgery	Post-surgery	*p* values
Education, n (%)			
Primary school	15 (20.55)	14 (19.18)	NA
Secondary school (high school)	28 (38.36)	29 (39.73)	
Vocational certificate	9 (12.33)	9 (12.33)	
Bachelor degree or higher	21 (28.77)	21 (28.77)	
Education category, n (%)			
Primary school	15 (20.55)	14 (19.18)	0.317
Higher than primary school	58 (79.45)	59 (80.82)	
Employment, n (%)			
Employed	55 (75.34)	60 (82.19)	0.059
Unemployed	18 (24.66)	13 (17.81)	
Occupation, n (%)			
Professional	3 (5.45)	2 (3.33)	NA
Semi-professional	5 (9.09)	6 (10.00)	
Arithmetic skill job	3 (5.45)	4 (6.67)	
Skilled worker	10 (18.18)	8 (13.33)	
Semi-skilled worker	15 (27.27)	19 (31.67)	
Unskilled worker	13 (23.64)	14 (23.33)	
Monk	6 (10.91)	7 (11.67)	

Table 2 Social outcomes (cont.)

Social outcomes	Pre-surgery	Post-surgery	*p* values
Occupation category, n (%)			
Professional/Skilled worker	36 (49.32)	39 (53.42)	0.317
Unskilled worker /monk/unemployed	37 (50.68)	34 (46.58)	
Income per month (Baht), n (%)			
No income	25 (34.35)	21 (28.77)	NA
1,000 – 5,000	9 (12.33)	12 (16.44)	
> 5,000 – 10,000	17 (23.29)	16 (21.92)	
> 10,000 – 30,000	16 (21.92)	17 (23.29)	
> 30,000 – 50,000	6 (8.22)	5 (6.85)	
> 50,000	0 (0)	2 (2.74)	
Income category, n (%)			0.206
No income	25 (34.25)	21 (28.77)	
Having income	48 (65.75)	52 (71.23)	
Marital status, n (%)			
Single	46 (63.01)	42 (57.53)	NA
Married	22 (30.14)	23 (31.51)	
Divorced	5 (6.85)	8 (10.96)	
Marital category, n (%)			
Single/divorced	51 (69.86)	50 (68.49)	0.706
Marriage	22 (30.14)	23 (31.51)	
Having a child, n (%)			
Yes	20 (27.40)	24 (32.88)	0.103
No	53 (72.60)	49 (67.12)	
Driving, n (%)			
Yes	33 (45.21)	44 (60.27)	0.008*
No	40 (54.79)	29 (39.73)	
Median EQ-5D-5L score (range)			
Mobility		1 (1-4)	
Self-care		1 (1-2)	
Usual activity		1 (1-3)	
Pain/discomfort		1 (1-3)	
Anxiety/depression		1 (1-4)	
Mean utility (SD)		0.95 (0.08)	
Mean EQ visual analog scale score (SD)		85.77 (13.89)	

utility score was 0.95 ± 0.08. Mean EQ visual analog scale score was 85.77 ± 13.89. (see Table 2).

Impact of Covid-19 outbreak on employment status and income after surgery (Figure 1)

Although Covid 19 pandemic did not significantly affect employment rate of the patients in this study (94.52% vs 97.26% p = 0.414), the number of patients reported postoperative loss of income has increased significantly as compared to pre-pandemic period (2.74% vs 16.64%, p = 0.008) (see Figure 1).

Social factors and postoperative quality of life

The factors influencing better quality of life at postoperative period are shown in Figure 2. Compared by EQ VAS score, patients with higher EQ VAS were employed (mean EQ VAS 87.35 vs 78.46, p=0.036) and were able to drive (mean EQ VAS 89.36 vs 80.31, p = 0.006). Other social factors including education level, income, marital status, and parental status do not show significant impact on the quality of life.

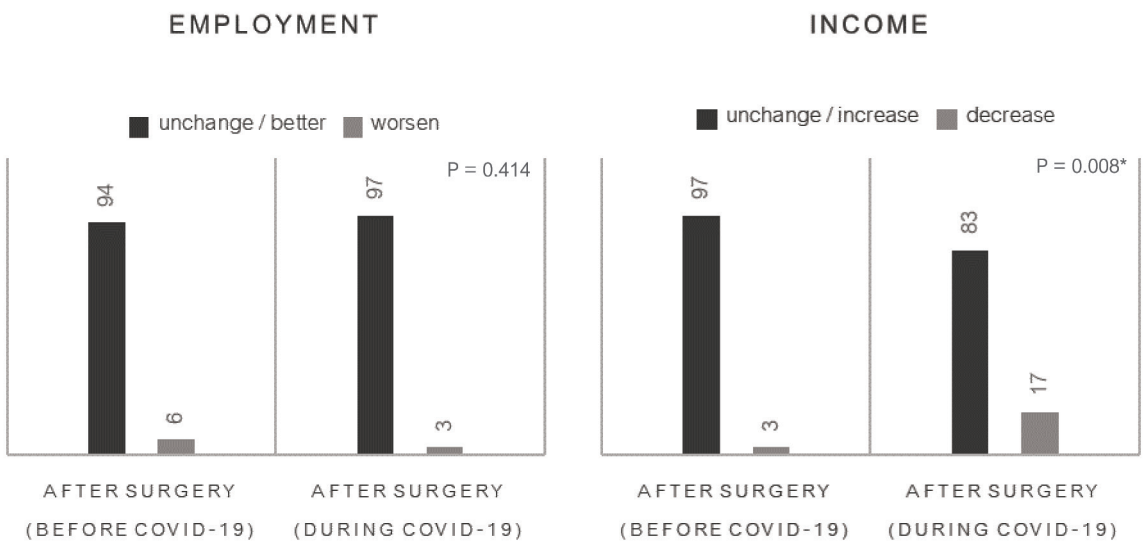

Figure 1 Impact of Covid-19 outbreak on employment and incomes

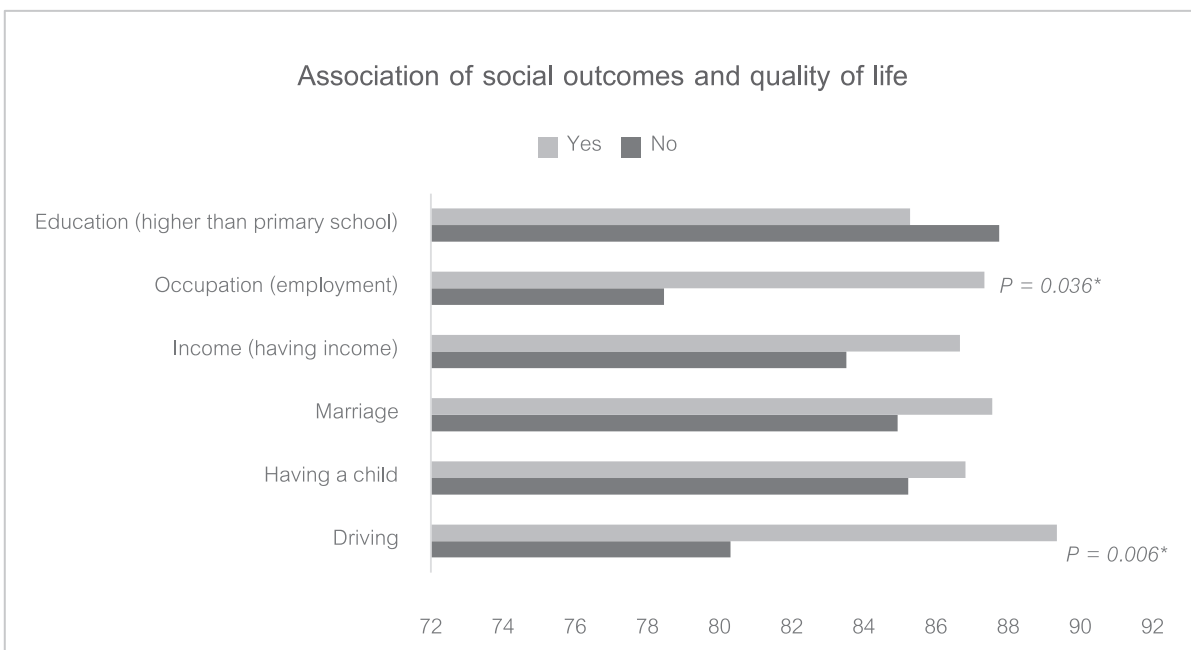

Figure 2 Factors influencing on better quality of life at postoperative period

Table 3 Best model to predict better quality of life upon multivariate analysis

Factors	Adjusted R-square	β-coefficient (95% CI)	*p* value
Driving	11.23	7.95 (1.57 - 14.34)	0.015
Employment		6.78 (-1.39 - 14.94)	0.102

Preoperative expectations and postoperative patient's satisfaction

The distributions of patient's expectations of epilepsy surgery are shown in Table 4. Their main goals were to become seizure-free, to live independently, and to be employed in 87.67%, 76.71%, 75.34%, respectively. Sixty-seven (91.8%) patients were satisfied with the surgical outcome and they would advise others suffering from epilepsy to pursue surgical treatment. There was one patient who would not advise others to seek surgical treatment because she suffered from memory impairment and hemiparesis after surgery. Five (6.85%) patients were not sure if they would advise others to pursue surgical treatment.

Table 4 Expectations and patient's satisfaction after the surgery in each aspect and suggestions for others to pursue the surgery

Aspects	At pre-surgery period	Satisfactions after the surgery
	Number of patients who expected improvements with the surgery in each aspect (%)	Likert median score (range)
Seizure control	64 (87.67)	6 (4-6)
Self-care	56 (76.71)	6 (3-6)
Ability to work	55 (75.34)	6 (3-6)
Marriage	15 (20.55)	5 (3-6)
Education	12 (16.44)	5 (3-6)
Suggestions for others to pursue the surgery	Yes, n (%)	67 (91.78)
	No, n (%)	1 (1.37)
	Not sure, n (%)	5 (6.85)

Discussions

To the best of the author's knowledge, this is the first study exploring a social outcome and quality of life after epilepsy surgery in Thai TLE patients. Among various studied social outcomes, there was significant change in driving status only which is similar to those earlier studies from the United States[14,17,23] and Sweden[24]. Other social outcomes in this study (education, employment, income, marital status) were not significantly changed after surgery.

Despite the average age of seizure onset of 12 years and a high seizure freedom rate in our series, there was almost no change in educational outcome. This is likely due to the fact that the mean age at surgery was 35 years which is well beyond studying age for the general population. Instead, they might be more interested in pursuing employment rather than an academic degree after a successful surgery. In the future study, it is worthwhile investigating if earlier surgical intervention during a patient's academic year would improve their educational outcome.

Although the number of patients who were employed had increased after surgery, it did not reach a statistically significant difference. In previous studies, the results were contradicting where some studies showed no change in employment[12-14], while others re-

ported increased employment[15,16]. The previous study in Thailand by Locharernkul et al.[15], has shown significant improvement of employment status following epilepsy surgery from unemployed to higher categories of professional achievement. The number of unemployed and no income individuals decreased from 66 to 25 cases (62.1 % reduction rate) after surgery ($p < 0.001$). The conflicting results among studies may be a result of a different population. Lincy et al. reported that younger age at surgery, shorter duration of epilepsy, longer follow-up duration, and lower income were associated with favorable employment outcomes, however, only shorter duration of epilepsy was independently predictive in multivariate models[13]. In the large prospective study by Edelvik et al., preoperative educational level and preoperative vocational status were associated with favorable employment outcomes[12].

Due to Covid-19 pandemic in Thailand, the government imposed a national lockdown in April-May 2020 followed by COVID-19 Prevention & Response Policy to limit the spread. The pandemic had affected the economy in many ways. This study evaluated the association of Covid-19 outbreak with employment and income in TLE patient and our findings showed that the number of patients who reported monthly income loss had increased significantly during Covid-19 outbreak (2.74% vs 16.64%, $p = 0.008$) but Covid-19 outbreak did not significant impact on employment. In the nationwide cross-sectional study in Thailand by Ruengorn et al.[25], on how Covid 19 affected the general population. Forty-nine percent of the general population reported income losses and 11.4% had lost employment which led to adverse mental health outcomes.

Overall, the quality of life of our patients was excellent. This study showed the factors influencing better quality of life at postoperative period were employment and ability to drive. The patients who were employed and able to drive tended to have better quality of life than those who were not. In the study by Auriel et al. employment was an important outcome measure that has been positively correlated with quality of life[26]. Study by Lee et al. suggested that unemployment was a contributing factor to depression[27]. In addition, the ability to drive had a significant impact on daily life. It allows a patient to live independently and as well as promotes employment and social activities. Seizure attacks while driving diminished QOL in epilepsy patients even though they only suffered minor injuries[28]. Therefore, improvement in driving status is a very important patient expectation of epilepsy surgery outcome. Results of previous and our studies support that gaining employment and ability to drive after surgery may improve quality of life.

For a majority of our patients, seizure control appeared to be the main goal of surgical treatment, followed by living independently, and being employed. Social relationship and education were of less concern. This is similar to the study by Lincy et al.[13] from India, a developing country's perspective. Interestingly, the results from the developed countries were different. Bower et al.[29] from the United States, showed driving was the most important aim. In the study by Taylor et al.[30] from Ireland, desire for work and driving were the main goals of the patients.

Overall, from this study result, surgery for medically refractory temporal lobe epilepsy improves social outcomes only in driving. Gaining employment and ability to drive after surgery are important factors influencing a better quality of life. Therefore, the vocational and driving rehabilitation program after epilepsy surgery was important. To enhance the employment outcome,

patients require occupational assessment to identify their individual abilities, limitations, and goals before epilepsy surgery. After surgery, they require continued support in vocational training and employment support.

There are several limitations in this study. First, the retrospective single-center study may incur patient selection bias. Second, a small sample size of a heterogeneous population certainly limits the statistical power of the analysis. Third, the patient's opinion about the expectation of epilepsy surgery for more than 2 years after having had surgery might not truly represent the opinions they had before surgery. Lastly, the COVID-19 pandemic situation in Thailand since January 2020 may be a confounding factor of socioeconomic outcome and quality of life of epilepsy patients in this study. Further prospective multicenter study could provide more definitive information on this topic.

Conclusion

Surgery for medically refractory temporal lobe epilepsy improves social outcomes only in driving status. Gaining employment and ability to drive after surgery are important factors which have a positive impact on the quality of life. Therefore, vocational and driving rehabilitation programs should be included in a comprehensive epilepsy treatment program to promote quality of life improvement in TLE patients after surgery.

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