Turkish Neurosurgery 2008, Vol: 18, No: 2, 114-124

Psychosocial Outcome after Extratemporal Epilepsy Surgery: A Prospective Clinical Study

Ekstratemporal Epilepsi Cerrahisi Sonrası Psikososyal Sonuçlar: Prospektif Klinik bir Çalışma

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Received: 20.12.2007
Accepted: 05.03.2008

ABSTRACT

AIM: The purpose of this prospective clinical study was to examine the short- and long-term psychosocial outcomes of a consecutive series of patients who underwent extratemporal lobe resection due to medically-refractory epilepsy.

MATERIALS and METHODS: The sample consisted of 23 consecutive patients and all patients completed a questionnaire assessing especially psychosocial outcome 6 months and 2 years after surgery. Results obtained at short- and long-term follow-ups were compared to baseline. Furthermore, the impact of seizure freedom on the psychosocial outcome was sought.

RESULTS: The results suggested that, psychosocial outcome was improved after surgery compared to preoperative status regardless of seizure status. At long-term follow-up, significant improvements were found in social and psychological variables ($p < 0.05$). Levels of side effects from medication were high at long-term compared to baseline ($p = 0.003$). Seizure free patients showed better psychosocial outcome than those who had seizure during the postoperative period, however; only the "impact of epilepsy" scale showed significant improvement at 6 months after surgery ($p = 0.02$).

CONCLUSION: These results provide evidence that surgery caused appreciable improvements in psychosocial well-being, however; seizure freedom is not key to improving the psychosocial life of patients who have undergone extratemporal lobe epilepsy surgery.

KEY WORDS: Epilepsy, Epilepsy surgery, Extratemporal epilepsy, Psychosocial outcome, Seizure, Seizure outcome, Quality of life.

ÖZ

AMAÇ: Bu prospektif klinik çalışmanın amacı ilaca dirençli ekstratemporal lob epilepsisi nedeniyle ameliyat edilen hastalarda kısa ve uzun dönem psikososyal sonuçları ortaya koymaktı.

YÖNTEM ve GEREÇLER: Psikososyal sonuçları değerlendiren soruları içeren anket formu ameliyat sonrası 6. ay ve 2. yılda 23 hasta tarafından doldurulmuştur. Kısa ve uzun dönem sonuçları ameliyat öncesi değerlerle karşılaştırılmıştır. Ayrıca, nöbetin psikososyal sonuçlar üzerine olan etkileri de araştırılmıştır..

BULGULAR: Ameliyat öncesi değerlerle karşılaştırıldıklarında, ameliyat sonrası kısa ve uzun sürede elde edilen psikososyal değerlerde ciddi artış bulunmuştur. Uzun dönemde, sosyal ve psikososyal değerlerde anlamlı artışlar görülmüştür. ($p < 0.05$). İlaca bağlı yan etkilerin algılanması ameliyat öncesine göre uzun dönemde anlamlı bir şekilde artış göstermiştir ($p = 0.003$). Psikososyal sonuçlar, nöbetsiz hastalarda nöbeti devam eden hastalara oranla daha iyi olmuştur, fakat sadece "epilepsi etki değeri" ameliyat sonrası 6. ayda iki hasta grubu arasında anlamlı fark göstermiştir ($p = 0.02$).

SONUÇ: Bu calışma göstermiştir ki, ekstratemporal lob epilepsi cerrahisi, hastalarda psikososyal hayatı olumlu etkilemiştir, fakat ameliyat sonrası geçirilen nöbet, psikososyal hayatın iyileşmesinde anahtar rol oynamamaktadır.

ANAHTAR SÖZCÜKLER: Epilepsi, Epilepsi cerrahisi, Ekstratemporal epilepsi, Nöbet, Nöbet sonuçları, Psikososyal sonuçlar, Hayat kalitesi.

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INTRODUCTION

Extratemporal epilepsies require careful preoperative diagnostic studies because of difficulty in both the lateralization and localization of the epileptogenic focus. Recent advancements in diagnostic modalities in terms of imaging and electrophysiological tools have led to improvement in seizure outcome. Resections out of temporal lobes even in crucial areas have been performed precisely without major neurological deficits particularly with improved surgical techniques. The surgical technique related to extratemporal resections have been well-described elsewhere in the literature (23, 24).

During the last two decades physicians dealing with epilepsy have witnessed that surgical treatment of success is not dependent on one factor, such as good seizure outcome, but is rather a complex and multifactorial construct that also depends on the patient's level of psychosocial adjustment (39). It has been well recognized that epilepsy patients suffer significant psychosocial problems compared to people without epilepsy. These include high levels of anxiety and depression (18, 28, 34, 41), poor self-esteem (11), decreased level of mastery and negative affect (12). People with epilepsy are more likely to be un- or underemployed (29), and lower rates of marriage and greater social isolation have been noted in epileptic patients (8). They often feel stigmatized by their condition (3). Recent reports conflict on relations between seizure freedom and improvements in psychosocial functioning after temporal lobe epilepsy surgery. Some studies suggest that favorable psychosocial outcome is dependent mainly on being completely seizure free (16, 26), suggesting that patients with postoperative seizures, even at reduced frequency, may have a worse outcome compared to their preoperative baseline status; other studies have demonstrated that freedom from seizures was not prerequisite for an improvement (19, 27), suggesting that patients may still suffer from psychosocial problems such as depression, anxiety, and stigma even after being seizure-free.

Interestingly, it has been shown that seizure-free patients described a range of psychosocial problems that appeared to arise directly as a result of being rendered seizure-free and these psychosocial problems were characterized as the "burden of normality" to capture the onslaught of new life experiences thrust on the previously chronically ill patient in the post-treatment phase (9, 39,40). The majority of studies examining psychosocial outcomes after surgery have focused on cases with temporal lobe epilepsy (1, 10, 21, 35, 36), however; only a small number of studies concerning psychosocial outcome after surgery in patients with extratemporal epilepsy have been reported (2, 25, 32, 41). These studies suggest that people with well-controlled seizures are less likely to report psychosocial problems. The focus of the present study is to evaluate psychosocial status before, and 6 months and 2 years after extratemporal lobe epilepsy surgery. We hypothesized that seizure-free patients would have a better psychosocial outcome than baseline or those patients who were not seizure-free. The results of follow-ups at 6 months and 2 years are reported.

MATERIALS AND METHODS

Patients

The study was conducted at the Montreal Neurological Institute (MNI) and the extensive evaluation process included discontinuation of medications for electroencephalographic (EEG) studies, depth electrode monitoring of seizures in selected patients, neuropsychological evaluation and, if indicated, amytal speech and memory testing and radiological investigation. The sample comprised the first 25 consecutive series of patients who underwent surgery due to extratemporal lobe epilepsy between June 1994 and July 1996. Since one patient died due to a car accident 15 months after surgery and one refused to answer the questionnaire, 23 patients were evaluated in this study. All had (a) confirmed diagnosis of epilepsy, with medically intractable seizures and no previous surgical treatment (b) were at least 17 years of age, and (c) had no history of chronic psychiatric illness or evidence of mental retardation. Baseline clinical and socio-demographic profiles are summarized in Tables I and II and Table III demonstrates surgical and histopathological details of the patients.

Postoperative evaluation

Patients were discharged on therapeutic dosages of at least one first-line anti-epileptic drug (AED). The first follow-up was performed at 6 weeks following the surgery and at 6 months in the 1st year and yearly thereafter through outpatient visits. The outcome was assessed independently by the

Table I. Demographic characteristics of patients evaluated in this study.

Factor	Baseline (n = 23)	Six months (n = 23)		Two years (n = 23)	
		Seizure-free (n = 15)	Persistent seizures (n =8)	Seizure-free (n =16)	Persistent seizures (n =7)
Age (yrs)	25.7±7.4	24.8 ± 7	27.6 ± 8.2	26.5 ± 8.3	24.1 ± 5
Sex (M/F)	13/10	9/6	4/4	9/7	4/3
Hand(R/L/Both)	16/6/1	11/3/1	5/3/0	10/5/1	6/1/0
School					
Othersa	6	-	1	-	1
Part-time	1	1	-	-	-
Full-time	4	7	2	5	4
Employment					
Unemployed	8	1	-	-	1
Part-time work	-	2	2	-	-
Full-time work	2	3	2	9	1
House wife	2	1	1	1	1

Othersa include students who could not maintain education due to epilepsy.

neurological and neurosurgical teams. All patients had magnetic resonance imaging (MRI), scalp EEG and neuropsychological evaluations during the follow-up period. In this study, seizure and psychosocial outcomes were evaluated at 6 months and 2 years postoperatively.

Seizure outcome

Outcome at 6-month and 2-year follow-up in relation to seizure control was based on Engel's classification, using all 12 subclasses (modified Engel classification) (14). For categorical comparisons, this classification was divided into favorable [(Engel class I and II)] and unfavorable [(Engel class III and IV)] seizure outcomes. Furthermore, the "seizure-free" group in this study included the patients who had been seizure-free since surgery without aura (Engel class Ia).

Psychosocial assessment

In this study, we used the Liverpool psychosocial battery (LPB), developed by Baker, et al. (4). Each patient who included in the study completed LPB questionnaire containing validated measures of physical, social and psychological domains, various questions about their epilepsy and questions relating to their demographic characteristics.

The physical domain included "seizure severity" and "adverse drug events" scales. The "seizure severity" scale is a 20-item patient-based scale divided into 2 subscales: perception and control (percept, 8 items) and ictal and post-ictal (ictal, 12 items). The first subscale includes questions pertaining to timing of seizures and their predictability. The second subscale contains questions about loss of consciousness, confusion, incontinence, falls, tongue biting and other injuries. Patients complete the scale for both their perceived major and minor seizures according to the duration of loss of consciousness and whether or not they fall to the ground. The "adverse drug events" scale is a 21-item (symptom) checklist developed to quantify patients' perceptions of the side-effects of AED treatment. The subjects were asked whether they had experienced any of 21 symptoms associated with AED treatment during the past month. For each symptom, they were asked whether it "always or often," "sometimes," "rarely," or "never" had been a problem in that time. Items in "seizure severity" and "adverse drug events" scales were rated on a 4-point Likert scoring system (22) where 1 is the least and 4 is the most severe score. A total score was calculated by summing all item scores. The higher the score, the more severe the seizure or the adverse events are perceived.

Table II. Clinical characteristics of patients evaluated in this study.

Factor	Baseline	Six months		Two years	
		Seizure-free (n=15)	Persistent seizures (n=8)	Seizure-free (n=16)	Persistent seizures (n=7)
1. Seizure characteristics					
Age at onset (yr)	8.2 ± 8.3	8.9 ± 9.1	7 ± 6.9	7.8 ± 9.1	9.2 ± 6.6
Duration of seizure (yr)	18.2±9.9	17.4±8.9	19.6±12	18.6±10.9	17.1±7.8
Frequency of seizure					
• Day	17.2±34.6	-	10	-	-
• Week	11.5±12	-	-	-	-
• Month	12.4±15.9	-	12.4±21.3	-	60
• Year	-	-	-	-	1.7±0.9
Aura (yes/no)	23/0	1/14	4/4	0/16	3/4
Perceived seizure					
• Major	3	-	2	-	3
• Minor	6	-	5	-	3
• Both	14	-	1	-	1
2. History					
Febrile seizure (yes/no)	3/20	1/14	2/6	3/13	0/7
Perinatal difficulties (yes/no)	4/19	1/14	3/5	1/15	3/4
Developmental delay (yes/no)	0/23	0/14	0/8	0/16	0/7
Trauma (yes/no)	6/17	5/11	1/7	5/11	1/6
Meningitis/Encephalitis (yes/no)	2/21	1/13	1/7	1/15	1/6
Status epilepticus (yes/no)	2/21	0/15	2/6	0/16	2/5
3. Imaging (MRI)					
• Mass lesions	4	2	2	3	1
• Dysplasia	15	10	5	11	4
• Mass + Dysplasia	1	-	1	-	1
• Othersa	3	3	-	2	1
4. SEEG (yes/no)	8/15	2/13	6/2	4/12	4/3

MRI: Magnetic resonance imaging; SEEG: stereoelectroencephalography. Othersa include lesions due to head injury.

Table III. Surgical characteristics and seizure outcome of patients evaluated in this study

Factor	Baseline	Six months		Two years	
		Seizure-free (n=15)	Persistent seizures (n=8)	Seizure-free (n=16)	Persistent seizures (n=7)
1. Surgey					
Age (yr)	25.4± 7.6	24.8 ± 7	26.6 ± 9.1	26.5 ± 8.3	23 ± 5.7
Side (Right/Left)	19/4	13/2	6/2	14/5	2/2
2. Location					
Frontal	15	9	6	11	4
Parietal	1	1	-	1	-
Central	3	2	1	2	1
Centro-frontal	3	2	1	2	1
Centro-parietal	1	1	-	-	1
3. Complications					
Neurological (yes/no)	3/20	3/12	0/8	2/15	1/6
Surgical (yes/no)	1/22	1/14	0/8	1/15	0/7
4. Histopathology					
FCD	15	10	5	11	4
ODG	3	2	1	3	-
Hamartoma	1	-	1	1	-
FCD + ODG	1	-	1	-	1
Othersa	3	3	-	2	1
5. Outcome					
Favorable		21 (91.3 %)	22 (95.7 %)		
Unfavorable		2 (8.7 %)	1 (4.3 %)		
Seizure freedom		15 (65.2 %)	16 (69.6 %)		

FCD: Focal cortical dysplasia; ODG: Oligodendroglioma. Othersa include gliosis (3 patients) and meningocephalic scar (1 patient).

The social domain includes two scales: “life fulfillment” and “impact of epilepsy” scales. The life fulfillment scale is a 10-item based scale aimed at measuring the discrepancy between patient’s actual and desired circumstances. A discrepancy score was calculated using the formula I(4-S), where I = important and S = satisfaction. The smaller the overall discrepancy score, the higher the level of fulfillment. The “impact of epilepsy” scale is a 9-item scale developed to assess the impact of epilepsy and AED on individuals’ relationships with friends and family, social life, employment, health, self-esteem, plans for the future and standard of living. A total impact score was calculated by summing all item scores. The higher the score, the lower the impact of the epilepsy perceived. Again, a 4-point Likert scoring system was used in the social domain scales (22).

The psychological domain includes the “mastery” and “affect balance” scales. The “mastery scale” is a simple 7-item scale using a Likert scoring system (22), where the total score is the sum of the item scores and the higher the total the greater the level of perceived internal control. The “affect balance” scale was designed to detect reactions to everyday life stresses and considers psychological well-being to be a balance between negative and positive affect. The scale contains 10 items using a yes/no format with a score of + 1 for yes and - 1 for no. The overall score is the summation of pluses and minuses. Positive and negative results mean happiness and sadness, respectively. Evidence of the validity and reliability of all scales had been examined in earlier studies and was published previously (5-7, 17, 31).

Statistical Analysis

The data were analyzed using the SPSS computer software (SPSS version 11.0.1; SPSS Inc., Chicago, IL). Tests of significance for dichotomous data (Liverpool psychosocial battery and mean number of AEDs prescribed) used were the "Mann–Whitney U" test with exact probabilities corrected for ties, Kendall's b correlation coefficient corrected for ties, while "¯2" was used for categorical variables. For the purposes of analysis, overall seizure outcome was split into favorable (Engel's classes I and II) and unfavorable (Engel's classes III and IV) outcomes. The nonparametric "Mann-Whitney U" test was used for comparison between the preoperative and serial postoperative scores and scores obtained between 6 months and 2 years. The "¯2" test was used for categorical comparisons (favorable versus unfavorable seizure outcomes).

RESULTS

Seizure outcome

At 6 months and 2 years follow-ups, 21 (91.3%) and 22 patients (95.7%) were included in the favorable seizure outcome group (Engel class I and II), respectively. A total of 15 (65.2%) and 16 (69.6%) patients were completely seizure-free (Engel class Ia) without aura after extensive questioning regarding the presence or absence of aura at 6 months and 2 years after surgery, respectively, and no patients were left with a worse seizure frequency or severity following surgery (no Engel's class IVb). The comparisons between favorable and unfavorable outcomes or between freedom from seizure at 6 months and 2 years follow-ups showed no statistically significant difference (¯2, p > 0.05) (Table III).

Medication status

Prior to surgery, one patient (4.3%) was on monotherapy while 12 patients (52.2%) were taking two and 10 patients (43.4%) were on ? 3 AEDs with no patient drug-free. The mean number of AEDs taken before surgery was 2.5 ± 0.8. Carbamazepine (52.1%) was the most commonly prescribed AED followed by phenytoin (39.1%) before surgery. At 6-month follow-up, one seizure-free patient (4.3%9) who was operated due to a frontal tumor had stopped taking AEDs by himself and the remaining 22 patients were on medication. Of the 22 patients, 9 (39.1%) were on monotherapy while 13 (56.5%) were taking more than 2 AEDs. The mean number of AEDs at 6-month follow-up was found to be 1.7 ± 0.7 and again, carbamazepine (52.1%) was the most commonly prescribed AED. The comparison between baseline and 6-month follow-up regarding dose reduction in AEDs showed a statistically significant difference (Mann-Whitney U test; z = -3.1, p = 0.02). The comparison between seizure-free patients and those with rare or frequent persistent seizures with respect to the AED regimen at 6 months after surgery was not statistically significant (Mann-Whitney U test; z = -1.8, p = 0.09).

At the long-term follow-up (2 years), 9 (39.1%) had stopped AED treatment. Of the 14 remaining patients, eight (34.7%) were receiving monotherapy and 6 (26%) were on two or more AEDs. The mean number of AEDs prescribed was 1.5 ± 0.7. The comparison between baseline and 2-year follow-up regarding dose reduction in AEDs showed a statistically significant difference (Mann-Whitney U test; z = -3.1, p = 0.02). The difference between patients who were seizure-free and those who continued to have seizures 2 years after surgery showed no significant difference in terms of dose reduction (Mann-Whitney U test; z = 0.0, p = 1.0). The comparison between short- and long-term follow-ups with respect to reduction of AEDs also did not reach a statistically significant level (Mann-Whitney U test; z = -0.8, p = 0.37).

Sociodemographic data

Of the 23 patients, 11 (47.8%) were students at the time of surgery. Prior to surgery, six (54.5%) could not go to school due to epilepsy, one (9%) was going to school part-time and four (36.4%) were at the school full-time. At 6-month follow-up, one patient (9%) who was not seizure-free could not go to school and another seizure-free patient (9%) was going to school part-time while 9 (81.8%) were going to school full-time. At 2-year follow-up, one seizure free student had graduated from law school and begun to work full-time. Of the remaining 10 students, 9 (90%) were going to school full-time and one student who was not seizure-free at 6-month and 2-year follow-ups could not continue his education due to seizures. Overall, surgery had caused improvement regarding a shift from part-time to full-time school attendance at both short- and long-term follow-ups.

Before surgery, 2 (16.6%) patients were employed full-time and 2 (16.6%) were housewives. Eight patients (66.6%) lost their job due to the seizures. However; at long-term follow-up, 9 of 12 patients (75%) were employed full-time. As can be seen in Table 1, seizure-free patients in general continued to work over time, and a few had also progressed from part-time to full-time employment.

Psychosocial outcomes

Table IV demonstrates the mean scores regarding subscales included in the LPB.

Seizure type and perceived seizure severity score

Six (26.1%) patients reported having minor seizures; 3 (13%) major seizures; and 14 (60.9%) both minor and major seizures before surgery. The corresponding values were 5 (21.7%), 2 (8.7%) and 1 (4.3%) at 6-month and 3 (13%), 3 (13%) and 1 (4.3%) at 2-year follow-up, respectively. The comparisons for "major seizure severity" scores between baseline and 6 months (Mann Whitney U test; z = -1.3, p = 0.16), baseline and 2 years (Mann Whitney U test; z = -0.1, p = 0.28), and 6 months and 2 years (Mann Whitney U test; z = -1.01, p = 0.17) did not show statistically significant differences.

Adverse drug event scale

Irrespective of freedom from seizures, the levels of reported side effects of AED were particularly high at follow-ups and the differences compared to baseline were statistically significant at 6 months (Mann Whitney U test; z = -3.1, p = 0.002) and 2 years (Mann Whitney U test; z = -2.9, p = 0.003). Interestingly, the perceived side effects at 2 years was high compared to 6 months but the difference was not found to be significant (Mann Whitney U test; z = -0.08, p = 0.93). The majority of patients who were taking AEDs after surgery said they worried "a lot" or "some" about the possible side effects of their medication. The most commonly experienced side effects were sleep disturbances (reported by 28.6%), double or blurred vision (by 28.6%), difficulty concentrating (by 22.7%), and skin problems, such as acne, rash (by 18.2%) during follow-up. High scores on the "adverse drug event scale" indicate that the medication significantly interferes with many aspects of their lives.

Life fulfillment scale

The patients were satisfied with some aspects of their lives compared to baseline, including family life, close friendships, marriage, leisure activities, social life, health, self-esteem, job, job security and standard of living. Mean "life fulfillment" scores were significantly lower (better) at 6 months (Mann Whitney U test; z = -2.5, p = 0.01) and 2 years (Mann Whitney U test; z = -3.3, p = 0.001) following surgery compared to baseline.

Table IV. Mean (± standard deviation) scores of domains of Baker test before, 6-month and 2-year after surgery.

Domains	Baseline (23)	Six months (23)	Two years (23)	P*	P†	P‡
1. Physical						
Seizure severity scale (major)	54.2 ± 7.9	58.3 ± 3.7	54 ± 6.6	NS	NS	NS
Adverse drug event scale	58.2 ± 8.4	67.6 ± 11.7	68.9 ± 9.4	0.002	0.003	NS
2. Social						
Life fulfillment scale	40.8 ± 14.1	27.2 ± 18	22.5 ± 18.3	0.01	0.001	NS
Impact Scale	17.6 ± 5.9	22.3 ± 8.8	28.2 ± 6.3	NS	0.00001	0.02
3. Psychological						
Mastery Scale	17.2 ± 2.6	18.1 ± 3.5	19.7 ± 2.1	NS	0.001	NS
Affect-balance scale	0.3 ± 3.6	0.6 ± 2.5	2 ± 2.8	NS	NS	NS

NS: Not significant.

***P*:** Baseline versus 6-months after surgery.*

***P†:** Baseline versus 2-year after surgery.*

***P‡:** Six-month versus 2-year after surgery.*

Perceived impact of epilepsy (impact scale)

The patients were asked to what extent they felt their epilepsy and its treatment affected a number of different aspects of daily living. During the preoperative period, a high percentage of patients reported that their condition negatively affected their standard of living and their feeling about themselves in a substantial manner. Following surgery, the patients stated that epilepsy had less impact on their lives and a significant difference was found between the mean scores at long-term follow-up compared to baseline (Mann Whitney U test; $z = -0.1$, $p = 0.00001$). Furthermore, at long-term, the patients believe that epilepsy did not affect the various aspects of their daily lives a lot compared to the results obtained at short-term (Mann Whitney U test; $z = -1.0$, $p = 0.02$).

Mastery scale

Following surgery, the patients had more mastery and a significant number of patients reported that their sense of control had improved. Mean mastery scores obtained at short- and long-term follow-ups were always higher than those of baseline but the difference was significant only at 2-year follow-up (Mann Whitney U test; $z = -0.1$, $p = 0.001$).

Affect balance scale

In general, feeling of well-being was greater after surgery regardless of seizure outcome but the comparisons between baseline and short and/or long-term follow-up did not reach a significant level (Mann Whitney U test; $z = -1.3$, $p > 0.05$).

Seizure and psychosocial outcomes

The mean and standard deviations for the LPB scores at baseline, 6-month and 2-year follow-ups are compared in Table V. At short- and long-term follow-ups, various psychosocial scales, particularly "life fulfillment", "impact" and "mastery" scales were better in seizure free patients and feelings of well-being were greater as well at long-term follow-up. Antiepileptic drug side effects perceived by the patients continued to be the major problems regardless of seizure outcome.

DISCUSSION

In this study, we evaluated the impact of seizure freedom on psychosocial outcomes after extratemporal lobe surgery. Two major results emerged from this study: a) surgery has significantly positive effects on psychosocial outcomes, and b) positive psychosocial changes are not limited only to individuals who became seizure-free after surgery.

Psychosocial status before and after epilepsy surgery has been studied in patients with temporal lobe epilepsy (13, 19, 20, 27, 30, 33, 37, 38), however; there has been a limited number of studies

Table V. Mean (± standard deviation) scores of Baker test before, 6-month and 2-year after surgery: seizure-freedom versus persistent seizures.

Domains		**Six months**		**Two years**			
	Baseline (23)	**Seizure-free (15)**	**Persistent seizures (8)**	**Seizure-free (16)**	**Persistent seizures (7)**	**P***	**P†**
Physical							
Adverse drug event scale	58.2± 8.4	69.5 ± 9.4	64.3 ± 15	70.8 ± 9.4	67 ± 9.8	NS	NS
Social							
Life fulfillment scale	40.8±14.1	22.7±17.1	35.7 ± 17.4	19.2±14.2	30.1 ± 24	NS	NS
Impact Scale	17.6 ± 5.9	25.3 ± 8.5	16.7 ± 6.7	30.3 ± 3.4	23.4 ± 8.7	0.02	NS
Psychological							
Mastery Scale	17.2 ± 2.6	18.9 ± 2.6	16.6 ± 4.6	20.1 ± 2.1	18.2 ± 2.2	NS	NS
Affect-balance scale	0.3 ± 3.6	0.4 ± 2.2	1 ± 3.2	2.1 ± 2.8	1.7 ± 2.9	NS	NS

NS: Not significant.

P: Seizure-free versus persistent seizures at 6-month follow-up.*

P†: Seizure-free versus persistent seizures 2-year follow-up.

concerning psychosocial status in patients with extratemporal epilepsy after surgery (2, 25, 32, 41). These studies have shown that successful alleviation of seizure through temporal or extratemporal lobe epilepsy surgery does not necessarily entail psychosocial benefits for the patient. Both patients who experience seizure freedom and those who continue to have seizures are at risk of either developing a mood disorder de novo, or exacerbating a preexisting condition (18, 34, 39, 40). Our findings are consistent with previous studies that seizure freedom after surgery does not guarantee a good outcome as perceived by the patient or family (33, 39). Our study disclosed that overall psychosocial domains are significantly better in short and long-term follow-ups than baseline. However; seizure-free patients showed more improvement in psychosocial outcome than those who had seizures after surgery and significant differences were not found in any domains at long-term follow-up. It is interesting that some psychosocial gains in our study were felt relatively early and were sustained over time whilst others (for example impact on the epilepsy scale and mastery scale) took longer to be influenced by the surgery and were only evident at 24 months. The reason patients feel that their psychosocial outcome improved at early assessment may be that there is a feeling of relief after surgery, which was translated into improved psychosocial life. However, we cannot explain with our results that why some psychosocial gains take longer to be influenced by surgery and are only evident at 24 months. Our results suggested that perceived treatment success is not dependent on one factor, such as the pathophysiological indicator of outcome; but is rather a complex and multifactorial construct that also depends on a patient's level of psychosocial adjustment (2, 38, 39, 40, 41). There was a trend for those patients who had never been seizure-free post-surgically to be experiencing both less happiness and less mastery than seizure-free patients, but these relations did not reach a significant level and considerable psychosocial problems still continued in seizure-free patients at long-term follow-up. Although surgery clearly resulted in significant improvement in seizure outcome, the link to psychosocial outcome was not as strong as we expected. Our findings suggest that years of poor psychological status may not be overcome by the sudden relief of seizures since epilepsy is a chronic disorder that necessitates long-term use of AEDs and it should not be expected that psychosocial difficulties automatically disappear as a result of successful surgery after living with seizures for many years.

The perceived AED side-effects were relatively high regardless of seizure outcome compared to baseline and the differences were significant although the mean number of AEDs prescribed after surgery was significantly low. Interestingly, seizure free patients at both short and long-term follow-ups reported more side-effects than those who had seizures. Our assessment of adverse drug effects was based solely on the patients' self-report so we had no objective measure against which to validate their responses.

Our results are consistent with some recent reports (13, 19, 33) showing that freedom from seizures is not a prerequisite for an improved psychosocial outcome after temporal lobe epilepsy surgery. On the other hand, some other studies claim that freedom from seizures is the key to success for good psychosocial outcome in temporal lobe epilepsy (16, 20, 30, 34, 37). We do not have a chance to compare our results with the studies mentioned above since our results belong only to extratemporal epilepsy, the clinical characteristics and seizure outcome of which are extremely different from temporal lobe epilepsy. In a recently reported study including patients with temporal lobe epilepsy, it wasshown that poor seizure control is associated with increased numbers of depressive symptoms and mood was found to be the most influential predictor of score in the quality of life (34). Furthermore, this study suggested that a previously reported strong relationship between seizure control and the quality of life reflects the relationship between seizure control and mood because seizure control's relationship to the quality of life becomes negligible when one takes mood into account (34).

We could speculate that surgery caused a significant improvement in seizure outcome that led to improvement in psychosocial status in extratemporal epilepsy compared to baseline but these improvements should not be attributed solely to freedom from seizures. Jones, et al. (19) examined the long-term psychosocial outcomes of patients who underwent temporal lobe epilepsy surgery and compared them with a group of medically managed patients. In this study, the surgical group showed a better psychosocial outcome than the medically managed group but there were no significant differences between the seizure-free patients and those with seizures in terms of composite psychosocial outcomes. Reid et al. (27), using the LPB model (4), failed to show a direct correlation between freedom from seizures and all aspects of LPB domains, suggesting that seizure reduction and not necessarily seizure cessation is an important positive surgical outcome. Recently, Dupont, et al. (13) showed that psychosocial outcome was independent of seizure outcome and freedom from seizures was not a prerequisite for an improved psychosocial outcome in a group of patients who had undergone mesial temporal lobe epilepsy surgery.

Recently, a limited number of studies evaluated psychosocial outcome in patients undergoing extratemporal lobe epilepsy and showed no association between general psychopathology, depression or anxiety, and seizure outcome (20, 32, 41). Likewise, it has been shown that seizure severity, frequency, and AED polytherapy are not directly associated with psychosocial variables, including anxiety and depression after extratemporal lobe epilepsy (18, 25). An interesting study comparing patient-perceived sexual outcome between temporal and extratemporal lobe resections showed that patients who underwent temporal lobe resections reported a decrease in desire for sexual intercourse compared to those who had extratemporal lobe resections (2). Taken together, our findings support above mentioned studies included patients who underwent extratemporal lobe epilepsy surgery and would suggest that although seizure freedom is the goal of epilepsy surgery, it is not fundamental for the patient’s psychosocial well-being.

Taking our results into account, the main concern is “why is there no significant association between seizure freedom and the psychosocial variables studied here?” The authors contributing to this study think that the answer can only be explained by the psychosocial syndrome, which was termed the “burden of normality’ by Bladin, et al. (40). The results of some recent studies showed that patients who had been seizure-free or experienced auras only were significantly more likely to report symptoms, compared to patients who had experienced overt seizures after temporal lobe epilepsy surgery (15, 38-40). These studies claimed that external demands placed on patients who are rendered seizure-free may increase dramatically, on the assumption that they have been “cured”. This, in turn, may heighten the patient's awareness of a discrepancy between postoperative expectations and their performance, thereby contributing to behavioral features of burden of normality (38, 39). Psychosocial changes described by patients include a need to prove oneself as “normal” and to “make up” for time lost as a result of the limitations previously imposed by the illness (39). This may be accompanied by the report of excessive activity in physical exercise, work, domestic duties, or socializing (15, 38-40). These findings are consistent with our results that the burden of normality arises from a process of adjustment as the patient learns to become well and this explains why seizure-free patients did not show significant improvement compared to patients who had seizures after surgery in the present study. It seems that psychosocial consequences of epilepsy may persist as independent sources of distress after successful surgery and as Ferguson and Rayport quoted “perhaps you can not take years of deformity and cut it off with just a knife” (15).

CONCLUSION

In conclusion, this small clinical prospective study has shown that surgery clearly improved psychosocial outcome in patients with extratemporal epilepsy and successful seizure surgery appears to be truly “life changing.” Seizure freedom is an important goal of epilepsy surgery but is not only the key to success in psychosocial life. We emphasize that studies such as this one should be prospective and longitudinal, and should cover larger number of patients with extratemporal epilepsy in order to produce more meaningful statistical data.

Acknowledgements

The authors thank Fusun Kobas Tanriverdi for her technical help while preparing this article. T.T is a clinical fellow at the Department of Neurosurgery, Section of Epilepsy Surgery, at Montreal Neurological Institute, McGill University, Montreal, Quebec, Canada and is supported by a scholarship provided by the “Mark Rayport & Shirley Ferguson Rayport Fellowship in Epilepsy Surgery.”

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