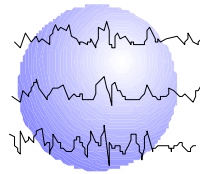


OUTCOME AFTER RIGHT TEMPORAL LOBECTOMY (RTL): THE PATIENTS' PERSPECTIVE

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REVISED ABSTRACT

RATIONALE: Patients who undergo epilepsy surgery begin the evaluation process and undergo the surgical procedure with expectations for seizure control and improved functional status. Patients being considered for nondominant right temporal lobectomy (RTL) receive optimistic statistical information for improved seizure control. The impact on patients' functional status and how surgery may change life experiences is often less clear.

METHODS: We surveyed patients post-operatively to evaluate their satisfaction with seizure control after RTL and to determine what life changes they experienced after the procedure. Questionnaires were mailed or personally given to patients who had had RTL. Questions addressed seizure control, medication status, work and school status, changes in psychosocial status, mood changes, and whether the individual would "do it again". Narrative comments were solicited for the "best" and "worst" part of the experience.

RESULTS: Forty-five patients received questionnaires. Forty-one (91%) were returned. Ninety-five percent (38/40) were glad that they had had surgery and 80% (34/45) "would do it again" without reservation. Seizure control was Engel Class I or II in 78%. Seventy-three percent were still on antiepileptic medications at follow-up of 0.5 - 11 years. Sixty percent were either in educational programs or were working. Overall psychosocial status had not changed in 67%. Of those who reported psychosocial changes, 70% (7/10) felt the change was positive. Only 6/34 reported a worsening of mood. Forty-two percent were on psychotropic medication. The narrative responses reflected experiences of pain, fear of what their individual results might be and "waiting for seizures" during pre-operative assessment. 2/45 spontaneously reported a decrease in sexual interest.

CONCLUSION: Overall, a majority of patients who had RTL achieve good to excellent seizure control, do well in vocational and social arenas, achieve personal goals and are pleased with the surgical outcome. They would go through the process again even if seizure control were not complete.

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INTRODUCTION

The medical goal in caring for patients with epilepsy is and has been to control the seizures. The patient's goals may be broader and consider additional aspects such as antiepileptic (AED) medication side effects; AED costs; and quality of life (QOL) measures: limitations on life style, the effects of having a label of epilepsy, inability to achieve independence, or other life goals. The refractory patient who has failed AED therapy may be a surgical candidate. The patient with nondominant, usually right, temporal focality is considered the ideal candidate for focal resective therapy, e.g. excellent chance of good seizure outcome and fewer risks of deficit compared to resections involving the dominant hemisphere. The patient may have goals other than just seizure control as the outcome measure. The medical team may not be aware of these other motivators or of the "hidden" concerns the patient may have. We felt that the patients' perspective on the experience would be useful in understanding our successes and our failures and provide us with insight for the education of future patients pre-operatively.

METHODS

A questionnaire of 14 items was developed (Figure 1) and either mailed to the patient or administered at an office visit to 45 patients who had had RTL between January, 1990, and January, 2001. Surgery was performed for treatment of refractory epilepsy. No tumor patients were included.

RESULTS

Forty-one of 45 questionnaires were returned for evaluation. Not all items were answered by all patients. One spouse returned the form noting the patients' death, a probable SUDEP. Eighteen were male; 23 were female. Age at surgery was 18 - 54 years (mean 37 years). Duration of epilepsy was 6 - 54 years (mean 24 years).

Patient follow-up ranged from 1.0 to 11 years. Table 1 reveals these results. RTL resulted in Engel Class I - II outcome in 75% of whom 77% were seizure free. No patients were worse. One patient went on to have a vagal nerve stimulator placed resulting in additional improvement.

Ten patients (25%) were successfully weaned off AEDs, while an additional 10 were able to reduce therapy to only 1 AED.

A change in social situation occurred in 33%. This was most often viewed as a positive result by the patient – e.g. marriage, living independently or with fewer support systems, getting a driver's license. Ten percent reported improved self confidence. Two patients spontaneously reported a decrease in sexual drive. There were two divorces.

Sixty-nine percent were employed (two in sheltered workshops, 1 volunteer). Four (10%) were in school at the time of the survey.

Most (59%) felt their mood was as good or better than prior to surgery; only 12% felt they were worse in this measure. Some psychoactive medication was being used in 37%. Of the 40 surviving responders, 98% were glad they had had the surgery. However 4 individuals felt they might “not do it again”. The narrative comments were variable and often quite individual. They did fall into some general categories and are delineated in Table 2 and Table 3.

DISCUSSION

Outcome after temporal lobectomy (TL) has been correlated with postoperative seizure control^{1,2,3}. RTL has been considered a risk factor for postoperative emotional or behavior problems⁴. Our RTL patients had good to excellent seizure outcome and are doing well psychosocially: working, going to school, feeling more confident, achieving life goals and independence. Mood was reported improved or good in the majority and worsened in a small minority. There were two patients with psychosis (5%) in this group of RTL patients consistent with reports of worsened psychological status in RTL^{2,4}.

It is notable that these patients did not overwhelmingly feel that seizure outcome was the most important outcome. Being on fewer or no medications and other positive accomplishments were just as important.

Of the four patients who “would not do it again”, two were seizure free. This report and the analysis of the “negative” responses suggest that some improvements in preoperative education, particularly regarding the importance of safety restrictions and increased attention to patient comfort (pain control, room temperature), would improve a surgical patient’s experience.

CONCLUSIONS

Patients who have RTL for control of refractory epilepsy have good outcomes: good seizure control, good vocational outcome, improved personal achievement.

Even if complete seizure control is not obtained, patients would do it again.

Improved preoperative patient education and increased attention to postoperative pain control may further enhance the patient experience.

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Table 1

Patient Responses to RTL Patient Perspective Survey**SURVEYS: SENT = 45, RETURNED = 41****SEIZURE OUTCOME**

Engel Class I-II	30
Engel Class III	10
Engel Class IV	0
SUDEP	1

MOOD OUTCOME

Better	10
Worse	6
Good	13
Up/Down	6

TREATMENT STATUS

Off AEDs	10
On AEDs	29
Weaned to 1 AED	10
VNS	1
Psych meds	16

OPINION RE SURGERY

Do it again	31
Not do it again	4
Uncertain	2
No answer	2

SOCIAL FUNCTION

Working	25
Further school or training	4
Social Change	13

GLAD TO HAVE HAD SURGERY

Positive	36
Negative	0
Uncertain	1
No answer	2

Table 2

**“What was the best part of the
evaluation?” Responses**

CATEGORY	NUMBER
SEIZURE OUTCOME	8
Being seizure free	3
Seizures less severe	2
Give me life back	1
Being off meds	1
Good results	1
LIFE CHANGES	11
Gave me hope	5
Getting driver’s license	3
Prevented going to nursing home	1
Should have done it sooner	1
Just doing it	1
PSYCHOLOGICAL FACTORS	6
Explained my poor memory	1
Chance to assess my life	2
Meeting others with same diagnosis	1
Family support	1
Confidence I can handle anything	1

Table 3

**“What was the worst part of going through
the evaluation?” Responses**

CATEGORY	NUMBER
FEAR	8
Of outcome	2
Of memory loss	2
Worry	1
Of complications	1
Of doing worse or dying	1
PAIN	7
Restrictions/Safety Issues	
Not being able to smoke	1
Restraints/safety precautions for grid	1
Post op restrictions on activity	1
RN (female) in Bathroom	1
ENVIRONMENT – ROOM COLD	1
PROCESS	5
Grid	1
MRI	1
Waiting for seizures	1
Testing	1
Long hospital stay	1
OTHER	4
Cost	1
Losing hair / wearing wig	1
Gaining confidence during recovery	1
Waiting to see if seizure free	1