

134 Psychosocial outcome and quality of life outcome

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Introduction

Common questions asked by patients before epilepsy surgery can be separated into those on the potential for a positive outcome and those on the risk of an adverse effect. Positive outcomes include seizure control, the possibility of a reduction or withdrawal of antiepileptic medications, retention of employment or the hope of new employment and a better job, the ability to drive, improvement in independent function in the community, and a better social relationship with family and friends. Adverse effects include pain and suffering, neurological deficits, impairment of memory and cognition, negative change in mood and personality, loss of independence and death.

This chapter deals with one of the most important outcomes of epilepsy surgery, the impacts of this surgery upon one's quality of life (QOL), especially in a social context. So important is this area, that one could even argue that if the surgery does not have a positive impact upon the quality of the patient's life that indeed it has failed.

We begin this chapter with a review of some of the most salient studies dealing with epilepsy surgery and quality of life overall. We then go on to specific topics of interest within the psychosocial and QOL domains, and we present some of our own data, not heretofore published, to support the conclusions we have drawn. Finally, we offer some guidelines to where research in this area might profitably go in the future.

Basic studies of general interest

What do we know of the concerns of patients with epilepsy outside of the routine clinical encounter? In particular, what do we know about psychosocial and QOL concerns? A Concerns Index has been developed with the Epilepsy Foundation of America, and studied in patients both before and after epilepsy surgery.¹ The Concerns Index was developed in two parts. First 81 patients with chronic epilepsy listed concerns in order of importance. Then experts selected items to construct a 20-item questionnaire. There are pertinent questions on driving, injury from seizures, job status, cognitive function, mood state and social function. Sixteen of 20 concerns were significantly reduced in a group of patients who had received anterior temporal resections, against a comparison group of patients awaiting surgery. However, the Concerns Index does not answer what epilepsy surgery patients actually seek out as the desired goals of surgery.

In fact, the desired goals expressed by patients about to undergo epilepsy surgery seem both logical and consistent across the world. One study from Australia specifically asked epilepsy surgery candidates 'What is the main reason you have sought surgical intervention?'² In order of descending rank, patients ranked firstly seizure control (62%), then driving (45%), new activities (38%), employment opportunities (35%), as the main goals for seeking surgery. In the Bonn series,³ the top 4 motives for surgery in descending order were: seizure control, independence, medication reduction, and improvement in vocational performance. In an Irish study,⁴ the most frequently cited aims for surgery in 69 preoperative patients were: gains in employment, driving, independence, improved socialization, and medication reduction.

In a study from the United Kingdom, the expectations of 70 presurgical candidates were studied by asking how they believed they would be on several self-report scales if surgery were successful in stopping their seizures.⁵ Preoperative patients had expectations that they would be in better control, and have better memory, more happiness, more independence, more interest in life, more hope, and to be more skillful and to be of greater value after successful surgery. The preoperative profiles were then compared to the self-ratings of 22 seizure-free patients 1 year after actual surgery. It showed that the presurgical expectations exceeded that reported by successful surgery patients 1 year after operation for several areas, such as interest in life, happiness, independence, and memory. This is a reminder that as in many areas of human psychology, expectations may exceed actual experience and that it could be important to counsel patients accordingly.

Outcomes after surgery can be divided into those based on observable measures, and those that are self-perceived. To understand the full impact of epilepsy surgery, both are needed. By observable measures we mean a quantity or status that some person other than the patient can appreciate. They include the core outcomes of seizure control, vocational and educational status, driving status, neuropsychological performance, neuropsychiatric behavioral changes, morbidity, and mortality.

However, other aspects of outcome, such as a patient's own sense of independence, or success in social relationships, are not so easy to quantify in the eyes of an observer. Similarly, the sense of self-worth is one that can only be made by the subject. Hence the measurement of self-perceived health status has become an important science.^{6,7} Separate from numerical measures of disease burden, health-related quality of life

(QOL) scales look at self-perceived sense of wellbeing in the major domains of physical health, mental health, social function, and general health. These are based on self-report questionnaires as distinct from classifications by an observer or investigator. It is beyond the scope of this chapter to discuss the background and processes leading to the development of the major measuring instruments in use except to point out that they need to satisfy the requirements of reliability, validity, and practicality. Reliability is the ability to measure variance that is not due to random error. Validity is the degree that the measure reflects the quality being assessed and not some other. Practicality or feasibility concerns the application of the instrument in real life, and includes the use of questions that can be clearly understood, and a form of administration that is not too burdensome.

The different measurement instruments and scales in use for assessing quality of life outcome after epilepsy surgery can be broadly separated into three groups. First, generic scales used in general health research which are not disease specific. Probably the most well known is the SF-36 of the RAND General Health Scales. Others include some of the instruments developed by the World Health Organization, such as the Quality of Life Assessment (WHOQOL) in its various forms. Second, are epilepsy specific scales. The first to be developed and used extensively was the Washington Psychosocial Seizure Inventory (WPSI).⁸ Adapted with epilepsy-specific questions, but built on the RAND SF-36 is the Epilepsy Surgery Inventory (ESI-55),⁹ containing 11 subscales covering a range of functions. Of the 55 items, 36 belong in the RAND SF-36, while 19 are specific to epilepsy concerns. Another more extensive instrument is the Quality of Life in Epilepsy (QOLIE)-89,¹⁰ which contains 89 questions. It includes the RAND SF-36 items, as well as selected items from ESI-55, and further expanded with additional questions. Others are sometimes specific to established use in different countries or regions, such as the Quality of Life Assessment Schedule (QOLAS), or EuroQol (EQ-5D).¹¹ Third, are those borrowed from other disciplines but thought also important in patients with epilepsy. Many are from the mental health world, such as the Beck Inventories for Depression (BDI), and for Anxiety (BAI), Hospital Anxiety and Depression Scales (HAD), Katz Adjustment Scales (KAS), Minnesota Multiphasic Personality Inventory (MMPI), the Brief Psychiatric Rating Scale, and numerous others.

Course of postoperative change

Changes in psychosocial and QOL functioning as demonstrated on any of the measures, whether observable or self-perceived, can certainly be expected to evolve over time. At what time point or points, should we gather the data? Is there a necessary time latency before changes become evident? The preoperative to postoperative interval over which measures were compared varied tremendously from as short as 2 weeks¹² to more than 30 years.¹³ More commonly, intervals chosen were at 1, 2 and 5 years, when patients were contacted both for information on seizure control and psychosocial outcomes.

At 3 months after surgery, some patients still have not completed basic healing, may have headaches and other symptoms

related to surgery, and may still lack stamina to return to all customary activities. This may seem too short an interval to determine postsurgical outcomes. Nevertheless, some studies had shown a divergence from preoperative quality of life even 3 months after surgery.^{14,15} It is unclear whether expectations for a positive outcome rather than actual life changes could have accounted for that. It is clearly too early to talk about gains in employment or independence just 3 months after surgery. Even at 6 months, while surgical healing is likely complete and most patients have resumed customary activities, there is question whether it may be premature to determine psychosocial outcome. For instance, while the commonest seizure-free interval required by driving licensing authorities in the US is 6 months, some require 12 months of seizure control before driving is permitted. Successful employment is another area that can take a longer time frame. The study by McLachlan *et al.*¹⁶ looked at QOL (ESI-55) at 6, 12, and 24 months in a group of patients who had undergone anterior temporal resection as compared to a medically managed group with similar disease severity. The study showed that significant differences in mean and several subscales in self-reported QOL between surgical and medical groups were greater at 24 months follow-up than at 6 or 12 months. A group time effect was also reported by Markand *et al.*¹⁷ There was greater improvement at 2-years than at 1-year follow-up. It is possible that changes in psychosocial status can continue after 24 months. By 5 and 10 years after surgery, a period of stability is more likely to have been established. At the other extreme, when follow-up extends to 30 or more years, new uncontrolled variables can be introduced, such as the appearance of new comorbid conditions that can contaminate the effect of surgery. In the case of children who received surgical treatment while still at school and receiving vocational training, there is a need for longer follow-up studies to learn of the impact of surgery on the maturing brain and personal development.

Bladin and Wilson in Australia,^{18,19} have stressed that the patient undergoes major adjustments after a major medical intervention that epilepsy surgery represents. The very relief obtained after seizure control is attained, transforming a life of chronic illness to one of relative well-being, can itself lead to new challenges. This challenge, 'the burden of normality', can lead to maladaptive psychosocial changes that are not anticipated. They reported that 35% of patients rendered seizure free experienced problems related to changing family dynamics, sometimes resulting in divorce. Another 20% of patients and families reported behavioral problems in dealing with the seizure-free state. Indeed, for many patients in whom epilepsy started relatively early in their life, their whole life had been on hold or constrained. Educational learning and life skills have been frequently compromised, and it may or may not have been possible to develop normal social relationships or work habits in the years of intractable epilepsy. Many have in addition to intractable epilepsy significant cognitive impairments that affect performance and judgment. The loss of disability income and social support can become a stressor. What has passed for the presurgical fabric of life may be a construct rather different from that in normal individuals without chronic illnesses. When that presurgical fabric of accommodation is transformed by complete seizure control, the set of complicated adaptations may unravel.

Seizure relief and other predictors of outcome

A reasonable expectation is that any improvement in psychosocial functioning and QOL after epilepsy surgery will reflect relief from seizures. Indeed, relief from seizures has been posited to be so important that unless there is complete relief, significant improvement in psychosocial functioning cannot be expected.^{20,21} As can be seen in Table 134.2 and in a later section, this relationship has been repeatedly affirmed in many studies. Furthermore, when seizure-outcome groups are stratified, the changes in QOL are graduated, with the best outcome in the completely seizure-free (and aura-free) group, next in those with residual auras, who in turn do better than those with a few seizures each year.^{15,17,22}

Other presurgical factors that might influence postoperative psychosocial outcome have not been consistently examined. In particular, the strong correlation between neuropsychological measures of mood and QOL measures²³ makes one wonder how premorbid mood status determines outcome after surgery. The reverse has been studied. One study found that preoperative scores on the emotional adjustment scale of the WPSI were highly correlated with subsequent depression.²⁴ Higher age at surgery was found to be negatively correlated with QOL measures in one study,¹⁵ but not in another.²² A single study reported that a higher presurgical IQ score correlated with better psychosocial outcome.²⁵

It is also of interest to ask if subjects with high self-ratings in function are the ones most likely to report continued wellbeing. This seems to be trend in employment, those already in employment before surgery are most likely to remain employed or to make gains in work status.

Long-term outcome 5 and 10 years after surgery at University of Washington

The University of Washington (UW) Regional Epilepsy Center prospectively performed neurological, neuropsychological, psychosocial, and EEG evaluations on 108 adults (age 16 and over; 55 women, 53 men; 94 right-handed, 14 left-handed; 107 Caucasian) with surgery on the left in 55 cases and on the right in 53 cases. Seventy-four of these patients were re-evaluated 5 years (± 6 months) after their surgeries and the remaining 34 patients were evaluated 10 years (± 6 months) after their surgeries. Preoperatively and at follow-up, patients were administered the Washington Psychosocial Seizure Inventory. Patients were divided across seizure outcome groups (Seizure free – no seizures whatever in the last 2 years of follow-up ($n=53$ total for both 5- and 10-year groups); significantly improved – at least a 75% improvement in the last 2 years of follow-up in comparison with the 2 years prior to surgery ($n=30$); not significantly improved – less than a 75% improvement in seizure frequency ($n=25$).

With the 5-year and 10-year groups combined, the preoperative and postoperative scores for the seizure-free patients on the WPSI are shown in Figure 134.1 using the paired Student *t* statistic applied to each variable independently with

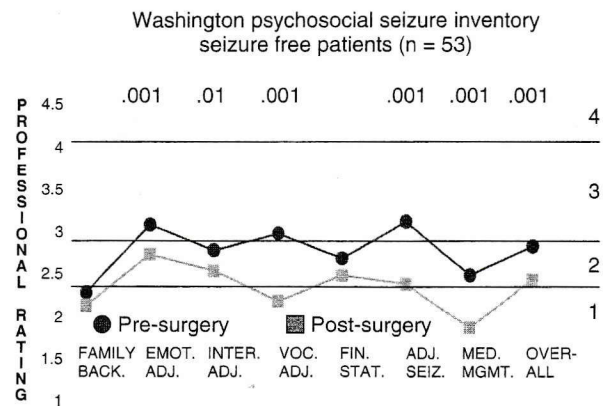


Figure 134.1 Preoperative and 5–10-year postoperative scores on the WPSI for the 53 patients who became seizure free. Improvements (lower scores) were noted on six of the eight clinical scales of the WPSI at the .01 level or better.

statistical significance set at the .01 level or better. Statistically better (lower) scores were obtained on six of the eight WPSI scales with substantial differences noted in all psychosocial areas except for family background and financial status. As would be expected, these are the areas that would be most difficult to change after surgery.

Figure 134.2 presents the results on the significantly improved patients. As can be seen, there are fewer statistically significant changes demonstrated on the WPSI and they were at levels less confidently associated with change from a statistical viewpoint. Nevertheless, they are convincingly greater changes than those of the not significantly improved group which are presented in Figure 134.3 where the changes seem to be little more than random fluctuations from one time to the next.

One can see that the results presented here are at deviance from other studies which showed no improvement in psychosocial function after surgery unless relief from surgery was complete. Several factors may be operative here, illustrating the complexity of their interactions. Those studies that have argued for complete seizure relief as the only important determinant have tended to lack the numbers to do detailed

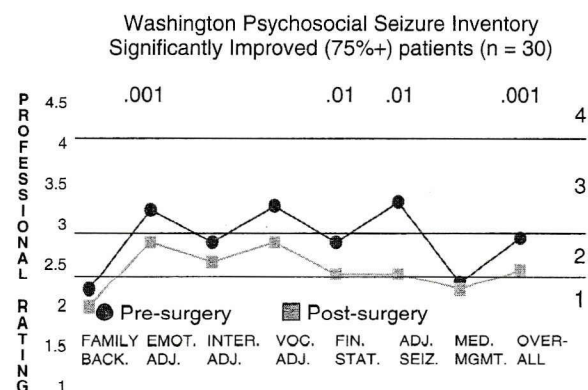


Figure 134.2 Preoperative and 5–10-year postoperative scores on the WPSI for the 30 patients who had significant improvement in their seizure frequencies (at least 75%). Improvements (lower scores) were noted on four of the eight clinical scales of the WPSI at the .01 level or better.

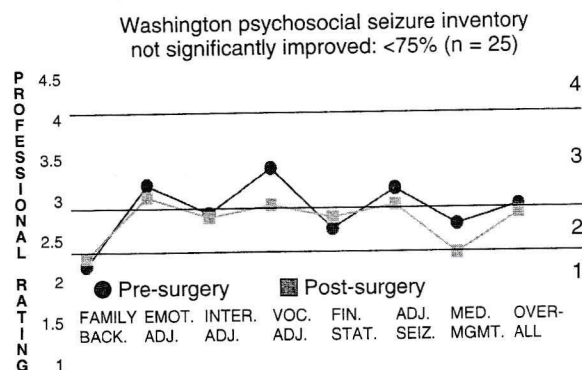


Figure 134.3 Preoperative and 5–10-year postoperative scores on the WPSI for the 25 patients who had no significant improvement in their seizure frequencies (less than 75%). Improvements (lower scores) were not observed on any of the eight clinical scales of the WPSI at the .01 level or better.

stratification of seizure status or did not take the extra steps to do so. We already mentioned other studies which showed that QOL improvements were incremental over a range of seizure outcomes.^{15,21,22} Two other factors are specific to the UW study. One is the extended length of postoperative follow-up of 5 and 10 years. This is anticipated to produce a more stable state that takes into account some earlier years of adjustment. Another is the type of psychosocial measure used. The WPSI was developed on an empirical basis, with every item anchored in performance in everyday life as judged by professionals.⁸ It was specifically not developed on the basis of an approach whereupon items are placed in groups based upon apparent content. It was also not developed on the basis of factor-analysis, a subjectively-based procedure which is not externally anchored, with factor names which are also not empirically anchored. As a consequence, less obvious changes in functioning may be missed.

Medication status after surgery

In general, patients who have had surgery, are either receiving fewer antiepileptic medications or are more likely to be on no medications in the postoperative period (Table 134.1). This is not too surprising, and undoubtedly strongly biased by patients who have been able to stop medications after becoming completely seizure free. Even though there is no set common protocol to discontinue antiepileptic drugs, particularly in light of follow-up information which showed that medication discontinuation carries a real risk of seizure relapse in those who initially appeared seizure free, many patients would nevertheless act on their own and taper and go off medical therapy when they judge themselves to be free of seizures. Even cautious clinicians who might not suggest to their patients that they should discontinue medications would still agree to a reduction in the number or dosage of drugs when patients are doing well.

Employment

Many but not all studies reported gains in employment status after epilepsy surgery. The most compelling were those that also compared surgically treated patients with a nonsurgical control group.^{1,13,25,27,30,32} Whenever additional enquiries had been made on the determinants that may influence employment after surgery, two have consistently been affirmed. One is that the employment status after surgery is correlated to whether the individual has been working, full-time or at least part-time before surgery.^{3,26,29} The other is that a gain in employment is strongly influenced by the seizure outcome, and that only seizure-free individuals are likely to maintain or gain new employment (Table 134.1). One study not only looked at improvements in employment and psychosocial status, but also at deterioration and reported that 94% of

Table 134.1 Effects of epilepsy surgery on antiepileptic medication (AED) status and employment status

Study	Medication status	Employment status
Augustine <i>et al.</i> 1984 ²⁶	(not studied)	Improved employment Unemployment related to preoperative unemployment, disability payments, psychiatric disease
Guldvog <i>et al.</i> 1991 ^{*13}	More likely off AEDs	Improved working ability in surgery group
Vickrey <i>et al.</i> 1995 ^{*27}	Reduced AED	Non-significant trend towards improved employment
Sperling <i>et al.</i> 1995 ²⁸	(not studied)	Improved in seizure-free patients And younger age at surgery
McLachlan <i>et al.</i> 1997 ^{*16}	Reduced AED	(not studied)
Reeves <i>et al.</i> 1997 ²⁹	(not studied)	Trend for improvement, correlated with ongoing education and full-time employment before surgery
Lendt, <i>et al.</i> 1997 ³	(not studied)	Overall improvement, Correlated with seizure-free status
Kellet <i>et al.</i> 1997 ^{*30}	(not studied)	Improved in surgery group if seizure free
Gilliam <i>et al.</i> 1999 ^{*1}	Seizure-free more likely off AED	No significant improvement
Markand <i>et al.</i> 2000 ^{*17}	Reduced AED	(not studied)
Jones <i>et al.</i> 2002 ^{*25}	(not studies)	Improved in surgery group Best when seizure free
Lowe <i>et al.</i> 2004 ³¹	Seizure-free more likely off AED	(not studied)

*with a non-surgical comparison group

patients who suffered deterioration had continued seizures after surgery.³

In one study,²⁹ being a student before surgery or obtaining further education after surgery were factors associated with employment after surgery. In two studies,^{3,28} age at surgery influenced outcome in that patients who remained unemployed after surgery were more likely to have been operated on later compared to those who became employed. This is a pointer perhaps to the importance of early intervention to permit not only the restoration of physical wellbeing, but also to allow a younger person the chance to gain or regain the educational and social skills that are a prerequisite to successful employment. By contrast, those already on disability payments before surgery were less likely to be employed afterwards.²⁶ It is not clear if those on disability payment before had more severe disease, more severe limitation in skills, or whether being established on disability payment itself served as a disincentive to return to the workforce.

School and education

Long-term studies of children or adolescents who received epilepsy surgery are relatively small in number and very different in design.³³ It is difficult to draw conclusions on the effect of surgery on the educational and psychosocial outcome of children and adolescents based on these reports. Only two used a QOL questionnaire with both preoperative and postoperative assessments but did not specifically discuss educational outcomes.^{34,35} The largest series of 50 patients who had temporal lobectomy in childhood from Mayo Clinic reported that 34 were either in school or employed at the time of follow-up.³⁶ Guldvog reported on the educational attainments of a cohort from Norway who had epilepsy surgery, as compared with a matching medically treated group.¹³ In looking just at patients who were still receiving education at the time of intervention, there was no significant difference in the length of education attained in the two groups. If anything, more surgically treated patients dropped out of school before having completed 7 years of education as compared to medical controls.

The lack of clarity in the literature more likely reflects on deficient data rather than lack of an effect. Many who have guided youngsters through successful surgery have been impressed by the transformation in behavior and attention that makes for enhanced learning at school. For those treated at a later stage in formal education, it could mean the difference between success or failure in graduation and certification.

Driving

Several studies specifically gathered information on driving status before and after surgery. This might be considered a relatively trivial matter in parts of the world where public transport is the norm. However, the privilege of driving is a vital part of independent living and a basis for work in most parts of North America. The Mayo Clinic series reported that the percentage of patients driving went from 20% preoperatively to 79% postoperatively.²⁹ Gilliam reported that 60% of patients were driving after surgery, while only 27% were able

to do so preoperatively.¹ Again the seizure outcome after surgery is the major determinant, since all driving authorities base the decision to issue a license on establishment of seizure control. Thus while 64% of patients who were seizure free successfully got a license postoperatively, none of the patients who continued to have seizures were able to do so.³⁷

Neuropsychiatric status

The Multi-Center Study on Epilepsy Surgery has provided the largest cohort of patients followed for psychiatric status before and after epilepsy surgery.³⁸ A total of 360 patients made self-reports using the Beck Depression Inventory, and the Beck Anxiety Inventory, and were administered the Composite International Diagnostic Interview, before surgery, and at 3, 12, and 24 months after surgery. The study confirmed significant overall improvement in symptoms of depression and anxiety after surgery, in keeping with prior reports. The decline in self-reported depression and anxiety was apparent as early as 3 months after surgery. Symptoms of depression and anxiety, present in 22.1% and 24.7% of preoperative patients respectively, declined by almost 50% postoperatively. Seizure control was significantly ($p=.02$) correlated with rates of postoperative depression: moderate to severe depression was present in 8.2% of seizure-free patients as against 17.6% of patients with continuing seizures. There is a similar but not statistically significant trend ($p=.09$) for postoperative anxiety. Localization or lateralization of the seizure focus were not correlated with depression or anxiety before or after operation.

The overall improvement in depression and anxiety after surgery can yet overlook two developments. First, a transient increase in symptoms in the first few weeks to months after surgery which fortunately resolve just as rapidly, with or without the use of psychotropic medications. Second, development of *de novo* psychiatric illnesses. One study reported that close to 50% of patients developed depression, anxiety, or mood lability in the first few weeks after surgery. Bladin reported that 54% developed anxiety in the postoperative period.¹⁷ Many of the patients improved within the first year. Certainly patients should be counseled before surgery that depression and anxiety can arise in the postoperative period, and offered treatment when indicated.

The literature on the *de novo* development of major psychiatric illness after epilepsy surgery is a long one. It includes historical hypotheses that are controversial. One is the concept of 'forced normalization' that describes the emergence of psychosis after the cessation of seizures, and others relate to the correlation of psychopathology to brain laterality, with schizophreniform symptoms linked to the dominant hemisphere, while mania and depression were linked to the nondominant hemisphere. Many of the observations were in the form of uncontrolled case series. Thus the frequency or incidence of such problems was unclear in the earlier reports. The latest Multi-Center Study yielded a *de novo* rate of 7.9% for depression, 9% for anxiety, and 1.1% for psychosis (mania, schizophrenia) in postoperative patients who did not have these manifestations before.³⁸ However, another series of 100 consecutive patients who had temporal lobe resections at a major center in Germany,³⁹ gave a somewhat higher incidence of *de novo* psychosis (11%), although the rate of

major depression (9%) was similar to that in the Multi-Center Study. The patients who developed postoperative psychosis were all rated to have had personality disorders before surgery, and some had persisting seizures while others were seizure free.

In the Norwegian study that compared 201 surgical patients to a medical control group of 185 patients, 6.7% of the surgical group developed de novo psychosis, while none occurred in the medical group. It is not clear whether the lower rate of postsurgical psychosis in the Multi-Center Study from the USA reflects different patient selection criteria between the USA and Europe, or differences in methodology in psychiatric evaluation.

Mortality

Patients with refractory epilepsy such as those who are candidates for surgical treatment are known to be at an increased risk for death. Often these are in the form of sudden unexplained death (or SUDEP) in addition to known accidents, suicide, or concurrent illness. Although the range of estimates for mortality can be large, the standard mortality ratio for patients with uncontrolled seizures at referral centers is close to 5, translating into an overall mortality of 1.3 per 100 person-years.⁴¹

In the Norwegian study, the survival of surgery patients was compared to those of medical controls.⁴⁰ There was no difference between the groups. However the effect of complete seizure control was not analyzed. A UCLA cohort of surgical versus non-surgical patients showed that surgically treated patients had significantly reduced mortality.⁴² The most complete follow-up data on mortality after epilepsy surgery had been that reported by Sperling over the years.^{43,44} In both the 1999 and 2005 reports, patients with recurrent seizures had significantly higher mortality (1.14–1.37 per 100 person-years) as compared with those who were seizure free (except for auras). Seizure-free patients had a mortality rate similar to that of the age- and sex-matched population at large. In short, persistent seizures after surgery are associated with an increased mortality rate similar to that of medically refractory patients, while successful epilepsy surgery normalized the risk.

Outcomes from quality of life scales

There has been a growth of interest in the assessment of quality of life by self-report questionnaires in the last decade. Selected findings from studies reporting on larger sample sizes are included in Table 134.2.

Table 134.2 Effects of epilepsy surgery on quality of life (QOL) measurements

Study	Surgery (n)	Control (n)	Measure	Follow-up	Results
Dodrill 1987 ⁴⁵	60	—	WPSI	1 yr	Improvement in 5/8 scales
Vickrey 1995a ²⁷	202	46	ESI-55 KAS	Mean 5.8 yrs	Improvement in 5/11 scales
Vickrey 1995b ²¹	133	—	ESI-55	> 1 yr	Improvement: seizure-free aura-free > aura-free > continuing seizures
McLachlan 1997 ¹⁶	51	21	ESI-55	6, 12, 24 months	Improvement in 6/11 scales at 24 m, better than at 6 or 12 m. Improved when seizure free or 90% reduction. Decline in others
Kellett 1997 ³⁰	94	36	Various	> 1 yr	Improvement when seizure free v 10 seizures a year or no surgery
Malmgren 1997 ⁴⁶	103	—	SF-36 HAD	> 2 yrs mean 4 yrs	Correlation with seizure outcome Seizure free: improved 7/8 scales
Wheelock 1998 ²¹	79	—	MMPI WPSI	2 m 1 yr	Improved only when seizure free
Gilliam 1999 ¹	125	71	ESI-55	> 1 yr	Improved 8/11 scales Correlation with mood, employment, driving, AED use but not seizure status
Selai 2000 ¹¹	25	15	QOLAS ESI-55 EQ-5D	Mean 1 yr	Improved 2/3 ESI-55 composite scores and QOLAS when seizure free or >75% seizure reduction
Markand 2000 ¹⁷	53	37	QOLIE-89	1, 2 yrs	Improved 10/17 scales Greater improvement at 2 yrs v 1 yr Seizure free aura free best outcome
Wiebe 2001 ¹⁴	40	40	QLIE-89	1 yr	Surgery group improved more than medical group
Spencer 2003 ¹⁵	231	—	QOLIE-89 BAI, BDI	> 2 yrs	Improvement apparent at 3 mo's Correlation with seizure outcome
Lowe 2004 ³¹	50	—	QOLIE-89	>2 yrs	Improvement when seizure free

For abbreviations of QOL instruments, see pages 5,6

All studies have shown an improvement in usually more than one quality of life domains. Some have shown an improvement as early as 3 months,^{14,15} while two reports noted that improvement was greater at 24 months than at earlier time points.^{16,17} Half of the studies employed a 'control' or comparison group of patients who did not have surgery: either because they did not have a localizable epileptogenic zone amenable for surgery, or because candidates declined surgery or were still awaiting surgery. All except one study¹ that specifically looked at the relationship between postoperative seizure control and QOL outcomes revealed a correlation between postoperative seizure status and QOL measurements: namely that a seizure-free status, or very few seizures, were correlated with higher QOL scores. The most detailed analysis of postoperative seizure outcome status with QOL measurements was that by Vickrey based on UCLA data.²² It showed significantly higher QOL scores in patients who were completely free of seizures and auras (Engel Class Ia), as compared to those who had residual auras, who in turn were separable in QOL measures from those with 2–12 seizures a year, and from those with >12 seizures a year. The latter had the lowest scores. Of interest, the study found no difference in QOL measure amongst seizure-free patients whether they remained on antiepileptic medications or not. That seizure-free and aura-free patients had the most pronounced improvement in QOL was confirmed by another study.¹⁷

There have been gratifyingly few indicators pointing to deterioration in psychosocial functioning after surgery, but it could be that this has not been looked into carefully. In order to answer this and other questions an ideal study would comprise both a surgery and medical treatment arm, with sequential QOL measures over time, starting at baseline

before intervention. The one study that satisfied this design did not have the details to address this issue.¹⁴ Anecdotal clinical experience suggests that deterioration in psychosocial function does unfortunately occur in a minority of patients, usually in those who have failed to obtain satisfactory seizure control sometimes with compounding neurological or cognitive deficits. Partial support comes from the Bonn series that found socioeconomic deterioration when it occurs to be related to insufficient seizure control.³ Markand¹⁷ found the only significant decline in QOL scores from baseline in patients with persisting seizures (not including auras) and that was in the social support domain of the QOLIE-89.

Summary

There is now a wealth of data that can be called on when counseling patients going through surgical evaluation and treatment. In addition to and in consequence of an improvement in seizure control, patients can rightfully anticipate an improvement in the potential to participate in the full range of life activities, which can extend to work and driving. As would seem to be obvious, seizure-free patients would no longer be exposed to the risk of sudden death as compared to those with continuing seizures. How long it takes for the positive benefits of epilepsy surgery to become apparent remains a subject of enquiry. Although some studies showed an improvement as early as 3 months after surgery, gains in life functions and employment will likely take much longer. Despite the consensus for positive change after successful surgery, we need to be mindful that there are others who can be unsettled or challenged by changes that come about after surgery.

REFERENCES

- Gilliam F, Kuzniecky R, Meador K et al. Patient-oriented outcome assessment after temporal lobe lobectomy for refractory epilepsy. *Neurology* 1999;53:687–94.
- Wilson SJ, Saling MM, Kincaid P, Bladin PF. Patient expectations of temporal lobe surgery. *Epilepsia* 1998;39:167–74.
- Lendt M, Helmstaedter C, Elger CE. Pre- and postoperative socioeconomic development of 151 patients with focal epilepsies. *Epilepsia* 1997;38:1330–7.
- Taylor DC, McKrackin D, Staunton H, Delanty N, Phillips J. Patient's aims for epilepsy surgery: desires beyond seizure freedom. *Epilepsia* 2001;42:629–33.
- Baxendale S, Thompson PJ. "If I didn't have epilepsy": Patient expectations of epilepsy surgery. *J Epilepsy* 1996;9:274–81.
- Vickrey BG, Hays RD, Hermann BP, Bladin PF, Batzel LW. Outcomes with respect to Quality of Life. In: Engel J Jr, ed. *Surgical Treatment of the Epilepsies*, 2nd Edition. New York: Raven Press, 1993:623–35.
- Dodrill CB, Batzel W. Issues in Quality of Life assessment. In: Engel J Jr, Pedley TA, eds. *Epilepsy: A Comprehensive Textbook*. Philadelphia: Lippincott-Raven Publishers, 1997:2227–31.
- Dodrill CB, Batzel LW, Queisser HR, Temkin N. An objective method for the assessment of psychological and social problems among epileptics. *Epilepsia* 1980;21:123–35.
- Vickrey BG, Hays RD, Graber J et al. A health-related quality of life instrument for patients evaluated for epilepsy surgery. *Med Care* 1992;30:299–319.
- Devinsky O, Vickrey BG, Cramer J et al. Development of the quality of life in epilepsy inventory. *Epilepsia* 1995;36:1089–104.
- Selai CE, Elstner K, Trimble MR. Quality of life pre and post epilepsy surgery. *Epilepsy Research* 2000;38:7–74.
- Robinson L, Saykin A. Psychological and psychosocial outcomes of anterior temporal lobectomy. In: Bennett T, ed. *Neuropsychology of Epilepsy*. New York: Plenum Press, 1992:661–7.
- Guldvog B, Loyning Y, Hauglie-Hansen E, Flood S, Bjonaes H. Surgical versus medical treatment for epilepsy. II. Outcome related to social areas. *Epilepsia* 1991;32:477–86.
- Wiebe S, Blume W, Girvin JP et al. A randomized, controlled trial of surgery for temporal-lobe epilepsy. *N Engl J Med* 2001;345:311–18.
- Spencer SS, Berg AT, Vickrey BG et al. Initial outcomes in the multicenter study of epilepsy surgery. *Neurology* 2003;61:1680–5.
- McLachlan RS, Rose KJ, Derry PA et al. Health-related quality of life and seizure control in temporal lobe epilepsy. *Ann Neurol* 1997;41:482–9.
- Markand OM, Salanova V, Whelihan E, Emsley CL. Health-related Quality of life outcome in medically refractory epilepsy treated with anterior temporal lobectomy. *Epilepsia* 2000;41:749–59.
- Bladin PF. Psychosocial difficulties and outcome after temporal lobectomy. *Epilepsia* 1992;33:898–907.
- Wilson SJ, Bladin PF, Saling MM, McIntosh AM, Lawrence JA. The longitudinal course of adjustment after seizure surgery. *Seizure* 2001;10:165–72.
- Rausch R, Crandall PH. Psychological status related to surgical control of temporal lobe seizures. *Epilepsia* 1982;23:191–202.
- Wheelock I, Peterson C, Buchtel HA. Presurgery expectations, postsurgery satisfaction, and psychosocial adjustment after epilepsy surgery. *Epilepsia* 1998;39:487–94.
- Vickrey BG, Hays RD, Engel J Jr et al. Outcome assessment for epilepsy surgery: The impact of measuring health-related quality of life. *Ann Neurol* 1995;37:158–66.

23. Perrine K, Hermann BP, Meador KJ et al. The relationship of neuropsychological functioning to quality of life in epilepsy. *Arch Neurol* 1995;52:997-1003.
24. Derry PA, Rose KJ, McLachlan. Moderators of the effect of preoperative emotional adjustment on postoperative depression after surgery for temporal lobe epilepsy. *Epilepsia* 2000;41:177-85.
25. Jones JE, Berven NL, Ramirez L, Woodard A, Herman BP. Long-term psychosocial outcomes of anterior temporal lobectomy. *Epilepsia* 2002;43:896-903.
26. Augustine EA, Novelly RA, Mattson RH et al. Occupational adjustment following neurosurgical treatment of epilepsy. *Ann Neurol* 1984;15:69-72.
27. Vickrey BG, Hays RD, Rausch R et al. Outcomes in 248 patients who had diagnostic evaluations for epilepsy surgery. *Lancet* 1995;346:1445-9.
28. Sperling MR, Saykin AJ, Roberts FD, French JA, O'Connor MJ. Occupational outcome after temporal lobectomy for refractory epilepsy. *Neurology* 1995;45:970-7.
29. Reeves AI, So EL, Cascino GD et al. Factors associated with work outcome after anterior temporal lobectomy for intractable epilepsy. *Epilepsia* 1997;38:689-95.
30. Kellett MW, Smith DF, Baker GA, Chadwick DW. Quality of life after epilepsy surgery. *J Neurol Neurosurg Psychiatry* 1997;63:52-8.
31. Lowe AJ, David E, Kilpatrick CJ et al. Epilepsy surgery for pathologically proven hippocampal sclerosis provides long-term seizure control and improved quality of life. *Epilepsia* 2004;45:237-42.
32. Fraser RT, Gummit RJ, Thorbecke R, Dobkin BH. Psychosocial rehabilitation, a pre- and postoperative perspective. In: Engel J Jr, ed. *Surgical Treatment of the Epilepsies*, 2nd edition. New York: Raven Press, 1993:669-77.
33. Strauss E, Westerveld M. Neuropsychological and psychosocial outcome in children. In: Lüders HO, Comair YG, eds. *Epilepsy Surgery*, 2nd edition. New York: Lippincott Williams & Wilkins 2001:855-863.
34. Van Empelen R, Jennekens-Schinkel A, van Rijen PC, Helders PJM, van Nieuwenhuizen O. Health-related quality of life and self-perceived competence of children assessed before and up to two years after epilepsy surgery. *Epilepsia* 2005;46:258-71.
35. Sabaz M, Lawson JA, Cairns DR et al. The impact of epilepsy surgery on quality of life in children. *Neurology* 2006;66:557-561.
36. Meyer FC, Marsh R, Laws ER, Sharbrough FW. Temporal lobectomy in children with epilepsy. *J Neurosurg* 1986;64:371-6.
37. Eliashiv SD, Dewar S, Wainwright I, Engel J Jr, Fried I. Long-term follow-up after temporal lobe resection for lesions associated with chronic seizures. *Neurology* 1997;48:1383-8.
38. Devinsky O, Barr WB, Vickrey BG et al. Changes in depression and anxiety after resective surgery for epilepsy. *Neurology* 2005; 65:1744-9.
39. Koch-Stoecker S. Psychiatric Outcome. In: Lüders HO, Comair YG, eds. *Epilepsy Surgery*, 2nd edition. New York: Lippincott Williams & Wilkins 2001:837-844.
40. Guldvog B, Loyning Y, Hauglie-Hanssen E, Flood S, Bjornaes H. Surgical versus medical treatment for Epilepsy. I. Outcome related to survival, seizures, and neurologic deficit. *Epilepsia* 1991; 32:375-88.
41. Nashef L, Fish DR, Sander JWAS, Shorvon SD. Incidence of sudden unexplained death in an adult outpatient cohort with epilepsy at a tertiary referral center. *J Neurol Neurosurg Psych* 1995;58:462-4.
42. Vickrey BG. Mortality in a consecutive cohort of 248 adolescents an adults who underwent diagnostic evaluation for epilepsy surgery. *Epilepsia* 1997;38(Suppl. 11):S67-9.
43. Sperling MR, Feldman H, Kinman J, Liporace JD, O'Connor MJ. Seizure control and mortality in epilepsy. *Ann Neurol* 1999; 46:45-50.
44. Sperling MR, Harris A, Nei M, Liporace JD, O'Connor MJ. Mortality after epilepsy surgery. *Epilepsia* 2005;46 (Suppl. 11): 49-53.
45. Dodrill CB. Commentary: psychological evaluation. In: Engel J Jr, Ed. *Surgical Treatment of the Epilepsies*. New York: Raven Press, 1987:197-201.
46. Malmgren K, Sullivan M, Ekstedt G, Kullberg G, Kumlien E. Health-related quality of life after epilepsy surgery: A Swedish multicenter study. *Epilepsia* 1997;38:830-8.