Title: Long term outcomes after epilepsy surgery, a retrospective cohort study linking patient reported outcomes and routine healthcare data.

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Highlights:

- **We conducted a retrospective analysis of post epilepsy surgery outcomes from 3 different data sources: case notes, patient questionnaires and a national anonymized linked health and population databank**
- **49% of patients were seizure free at last follow up (median follow up of 7 years) with 88% having at least a worthwhile improvement in seizure frequency following resective epilepsy surgery**
- **There was a significant increase in quality of life (QOLIE-31-P)**
- **There was a significant reduction for all cause hospital admissions post-surgery and reduction in anti-epileptic drug load post-surgery**

Abstract

Objective: To assess the long-term outcomes of epilepsy surgery between 1995–2015 in South Wales, UK, linking case note review, postal questionnaire and routinely-collected healthcare data.

Method: We identified patients from a departmental database and collected outcome data from patient case notes, a postal questionnaire and the QOLIE-31-P and linked with Welsh routinely-collected data in the Secure Anonymised Information Linkage (SAIL) databank.

Results: 57 patients were included. Median age at surgery was 34 years (11–70); median 24 years (2–56) after onset of habitual seizures. Median follow-up was 7 years (2–19). 28 (49%) patients were free from disabling seizures (Engel Class 1), 9 (16%) experienced rare disabling seizures (Class 2), 13 (23%) had worthwhile improvements (Class 3) and 7 (12%) no improvement (Class 4). There was a 30% mean reduction in total anti-epileptic drug (AED) load at five years post-surgery. 38 (66.7%) patients experienced tonic-clonic seizures pre-surgery verses 8 (14%) at last review. Seizure-free patients self-reported a greater overall quality-of-life (QOLIE-31-P) when compared to those not achieving seizure freedom. Seizure-free individuals scored a mean of 67.6/100 (100 is best), whereas those with continuing seizures scored 46.0/100 ($p<0.006$). There was a significant decrease in the median rate of hospital admissions for any cause after epilepsy surgery (9.8 days per 1000 patient days before surgery compared with 3.9 after $p<0.005$).

Significance: Epilepsy surgery was associated with significant improvements in seizures, a reduced AED load and an improved quality-of-life that closely correlated with seizure outcomes and reduced hospital admission rates following surgery. Despite this there was a long delay from onset of habitual seizures to surgery. The importance of long-term follow-up is emphasized in terms of evolving medical needs and health and social care outcomes.

Abbreviations:

AEDs, Anti-epileptic drugs; DRE, Drug resistant epilepsy; HS, Hippocampal sclerosis; IGRP, Information Governance Review Panel; QOL, Quality of life; SAIL, Secure Anonymous Information Linkage; VNS, Vagus nerve stimulator.

Key words:

Refractory epilepsy, Epilepsy surgery, Seizure cessation, Quality of life, Long-term outcomes

1 Introduction:

Epilepsy is a chronic condition with a prevalence of 50 million worldwide and an incidence of 2.4 million per annum (1). In Wales, approximately 30,000 people suffer with epilepsy (2). The main treatment of epilepsy is pharmacological intervention with anti-epileptic drugs (AEDs). However, a third to a half of patients develop seizures that are resistant to AEDs, referred to as drug resistant epilepsy (DRE) (3). DRE is commonly defined as a failure to achieve sustained seizure freedom after treatment with at least two appropriately chosen and appropriately used AEDs, in monotherapy or in combination (4-6). The reasons why DRE develops remains unknown (7). **Delineation and surgical resection of epileptogenic brain tissue is a treatment option with a strong evidence base for reducing or halting seizures and reducing AED dependence, along with beneficial outcomes on quality of life (QOL) in appropriately selected and evaluated cases (8-12).**

Delay from onset of habitual seizures and drug resistance to surgical treatment is well recognized with intervals of several decades in most case series (11-14). One reason for this delay may be poor knowledge of the available surgical options, and perception of patients, carers and treating physicians. The time to surgery probably impacts on morbidity and mortality (15), and those not proceeding to surgery have been found to be 2.4 times more likely to die than those who did have surgery (16). Life expectancy itself has also been shown to be on average five years longer in operated drug resistant epilepsy compared to those remaining on medical therapy (17).

A small number of studies have looked at epilepsy surgery outcomes beyond five years (18-23) with many others only reporting outcomes at three years or less (9, 10, 13). An important outcome, in addition to seizure freedom, is change in AED treatment load post-surgery; one review of outcome studies with more than five years follow up found that less than a quarter of studies included outcomes on AED changes and patient QOL measures (21).

We therefore set out to study the long-term outcomes of epilepsy surgery at our center, that serves a relatively stable population in South Wales, UK. We focused on seizure outcome measures, quality of life, AED use and hospital admissions rates. **We aimed to access three separate sources of information for our outcome measures: 1) the patients' clinical records, 2) a postal questionnaire including the QOLIE-P31, 3) a national secure database of anonymized health and social care records.**

2 Methods

Approval for the study was given by the hospital Continuous Service Improvement Office, Cardiff and Vale University Health Board, Wales, UK. We identified 84 patients from the epilepsy unit departmental database who had undergone resective epilepsy surgery between 1995 and 2015. We did not include patients where the primary aim of surgery was tumor resection or those undergoing vagus nerve stimulator (VNS) implantation. We obtained information for 84 patients by reviewing paper case notes and the hospital's online clinical records portal [electronic front end for clinical investigations, attendances and letters (from 2008)]. All patients had undergone evaluation with video-EEG telemetry, MRI and pre-operative psychological assessments. Patients operated before 2011 were evaluated with video-EEG telemetry at Kings College Hospital, London, and thereafter all evaluations were undertaken in Cardiff. Patients were operated by one of 2 neurosurgeons [RH (pre-2012) and WG (post-2012)].

2.1 Patient hospital records

From the patient's hospital records we determined changes in seizure frequency and character, time to surgery from initial diagnosis, changes in AEDs and any record of adverse surgical events or psychiatric, cognitive and visual problems (pre-surgical baselines were noted). We used Engel classification to determine seizure outcome at the most recent outpatient appointment, where one is the best outcome and four the worst, with subcategories for each class (appendix 1 – supplementary materials). This has good agreement with the ILAE outcome scale (24) but maintains subcategories for seizure type e.g., focal versus bilateral tonic clonic.

2.2 Questionnaire and QOLIE-31-P

A questionnaire was developed to identify the patient's current perspective on having experienced epilepsy surgery including their report of seizure frequency (daily, weekly, monthly, yearly and none in the past year), employment and driving status (appendix 2 – supplementary materials). We also included the QOLIE-31-P which was originally developed by Crammer to specifically assess the quality of life of people with epilepsy (25). The QOLIE-31-P takes into account the patients' perception of: levels of energy, emotional toll, daily activities, mental activity, medication effects, seizure attitudes and their feelings on quality of life overall (appendix 3 – supplementary materials). Responses to the QOLIE-31-P were scored according to standard instructions giving an overall score for each patient ranging from 1–100 (100 being the best QOL) (25). Given the large number, type and doses of AEDs to be assessed at different time points over a period of up to 20 years, comparison over time can be difficult. We therefore developed a system to calculate a drug load or burden with respect to the maximum recommended daily dose, as well as recording the total number of AEDs. For each AED, we calculated a ratio of total daily dose taken compared to the maximum recommended daily dose [from British National Formulary, March 2017(26)]. Thus, a patient taking the maximum recommended daily dose would score 1, a patient taking 50% of daily dose 0.5, and so forth. For example, a patient taking levetiracetam 1250mg BD would score 2500/3000=0.83 (3000mg being the highest recommended daily dose (26)).

2.3 Anonymised linked heath care records

We used the Secure Anonymous Information Linkage databank (SAIL) (Health Data Research UK, Swansea University) to anonymously link the list of patients having had resective epilepsy surgery to routinely-collected primary care and hospital admission records (27, 28). We included patients who were registered as living in Wales during the periods five years before and after the epilepsy surgery. We recorded the length of stay for all hospital admissions and total time registered as living in Wales before and after surgery excluding one month immediately before and after surgery to exclude specific peri-operative related hospital stays. We compared the rates of admission before and after surgery using a signed Wilcoxon Signed-Rank test.

All studies using SAIL data need independent Information Governance Review Panel (IGRP) approval but do not require specific NHS research ethics committee approval. This study obtained IGRP approval ref 0565.

3 Results

We identified 406 cases as having epilepsy and neurosurgery in our department, from which 84 were identified as having resective epilepsy surgery. 64 sets of case notes were available for review. We excluded a further seven cases [three had palliative not resective procedures, two insufficient case notes, and two did not have neurosurgery (incorrectly identified)], leaving a total of 57 patients for patient note review.

3.1 Results of hospital record review

Of the 57 patients forty-nine were right handed, seven left and one ambidextrous. 51% (29) of patients had a history of febrile seizures, 47% were noted to have not suffered a febrile seizure and one was undocumented. **Patients had a median age at surgery of 34, with the median time between onset of habitual seizures and surgery being 24 years (range 2–**

56). It would be important to record the time interval from consideration of epilepsy surgery to the surgery itself. However, we did not have access to these data. As a proxy, we recorded the date of video telemetry in 36 cases, there was a median interval of 12 months (range 6-36) between video-telemetry and surgery.

Median duration of outpatient follow up after surgery was seven years (range 1–19). **All 57 patients had 1 year of follow up, with 40 still being followed up at 5 years, 25 at 7-8 years, 22 at 10 years, 13 at 12-13 years and 3 at greater than 15 years.** Lateralization and histopathological diagnoses are shown in figure 1. We found a significant difference in the number of patients operated with left (n=28) and right (n=14) hippocampal sclerosis (HS) $p<0.02$ (one sample binomial test).

The type of surgery is summarized in table 1.

Type of Surgery	**Number of patients**
Anterior temporal lobectomy	40 (27 left, 13 right)
Selective amygdalohippocampectomy	7 (5 left, 2 right)
Lesionectomy	10. Temporal, n=4: Epidermoid x2, DNET x2 Frontal, n=4: Ganglioglioma, Epidermoid, cortical dysplasia x2 Parietal, n=1: DNET Occipital, n=1: Ganglioglioma

Table 1: Type of surgical procedure undertaken. DNET; Dysembryoplastic Neuroepithelial Tumor

3.1.1 Post-operative seizure outcomes

49% (28) of patients were at Engel class 1 (free from disabling seizures), 16%(9) class 2, 23%(13) class 3 and 12%(7) at class 4 (no worthwhile improvement) (figure 2a) at last follow up (median 7-years). Figure 2b demonstrates the change in time of Engle class of those patients who were followed up at 1, 5, and 7-8 years (N= 57, 40, 25 respectively) A more detailed breakdown of seizure type and frequency before and at one year following surgery was also determined (figure 2c), and of seizure type and frequency at long term follow up (figure 2d).

3.1.2 Post-operative morbidity outcomes

10.5% (6) patients suffered surgical site infections with three requiring cranioplasty and one requiring an intensive treatment unit (ITU) admission. Three patients experienced psychiatric events post-surgery that required inpatient stays. One of these required involuntary detention under the mental health act after attempting suicide by violent means. **40% (23) patients experienced at least partial upper quadrantanopia visual impairment** on formal testing.

3.1.3 Anti-epileptic drug usage

Patient follow up data reduced with increasing time post-surgery, and therefore, total drug consumption was calculated per capita (Figure 3). The mean number of AEDs pre-surgery was 2.35, at last clinic appointment this figure had dropped to 1.83, a reduction of 22%. Of the 20 patients who stopped AEDs entirely, only three remained seizure free with the remaining 17 restarting AED treatment for seizure recurrence. Of the three seizure-free patients, two stopped their AEDs, both stopped medication one year post-surgery and had follow up at three and five years post operatively. **The third patient attempted to come off medication at four years but unfortunately relapsed on this attempt and restarted carbamazepine. However, after a second attempt at medication withdrawal they**

remained seizure free at follow up, 13 years after surgery. Of the remaining 54 patients, 33 (61%) were on a reduced total AED load compared to pre-surgery, 13 were on the same and eight were on a greater AED load.

3.2 Results of postal questionnaire

Of the 84 patients identified, 34 (40%) returned postal questionnaire and QOLIE-P31 forms, all completing both questionnaire and QOLIE-P31. Four responses to the QOLIE-P31 were excluded due to incomplete responses to the questions obviating score calculations. Results of the questionnaire are summarized in table 2.

Table 2: Questionnaire responses for employment, driving and seizure status.

	Yes	No
Employment (Full or part time)	12	22
Driving	7	27
Seizure free	21	13

The seven patients who returned to drive did so at a mean of 3.5 years post-surgery. Patients' questionnaire responses to seizure frequency can be seen in figure 2d. Two patients (6%) experienced no reduction in seizure frequency, with the rest experiencing at least a one class reduction. 13 (40%) patients reported seizure freedom. No patients reported worsening seizures however, 3 patients reported that their QOL had decreased. 26 (76%) of the 34 patients reported that their QOL has improved to some extent (Figure 5).

3.3 QOLIE-P31 questionnaire

Scores were calculated from the 30 complete responses. The final score is a scale ranging from 0–100, with a score of 100 being the best possible QOL. The mean score was 55.2 (s.d. 21.7). Those free of seizures scored a mean of 67.9 whereas those who did not achieve seizure freedom scored 46.1, a difference of 21.6 (95% CI 7.0,37.9) $p<0.006$ (Mann-Whitney U).

3.4 Results of anonymized healthcare data

We were able to link 34 patients with routinely-collected healthcare data before and after surgery. The proportion of men, mean age at diagnosis and age at surgery were 38%, 10 years and 36 years respectively in this sub-group.

There was a significant decrease in the median rate of hospital admissions for any cause when comparing the five years after surgery with the five years immediately prior to surgery (3.89 days per 1,000 patient days after surgery compared with 9.84 days per 1,000 days before surgery $p<0.005$) see figure 6.

4.1 Discussion

We conducted an evaluation of long-term outcomes in patients having undergone epilepsy surgery in Cardiff, UK. We found that 49% of patients were free of disabling seizures (Engel class 1) at their most recent outpatient visit, a median of seven years post-surgery (Range 2–19). Our seizure outcome findings are similar to those reported by others five years post-surgery, (18-23). The majority of patients were taking fewer AEDs following surgery. QOLIE-P31 scores were significantly higher in those who achieved seizure freedom compared to those who did not. There was close correlation between seizure outcomes, subjective quality of life questionnaire responses and QOLIE-P31 scores in the postal questionnaire/QOLIE-P31 cohort. The majority of patients responding to the questionnaire reported a positive outcome after epilepsy surgery, even if not seizure free post-surgery. We found a measurable reduction in total AED dosing following surgery, using a metric of ‘AED load’, along with the total number of AEDs taken per person. We were able to link 34 of the patients (60% of cohort) with 5 years of routinely-collected anonymized healthcare data before and after surgery that showed a significant reduction in all hospital stays after surgery for this cohort.

We found significantly more left HS resections when compared to right HS resections in our series. This has also been reported by other centers. (29) The reasons are unclear, and we do not know the overall prevalence of all HS in our epilepsy population, though a higher prevalence of left compared to right HS has been reported by others (30, 31). We postulate that left HS could have been more likely to come to surgery because of more debilitating seizures (with loss of awareness), compared to right HS (32), or more likely to be present or be under follow at tertiary centers for the same reason.

Previous studies have reported AED use and seizure freedom (21, 33), we found it additionally helpful to develop a measure of AED burden as an outcome measure.

This showed a 30% reduction in drug dosage five years post-surgery in comparison to pre-surgery. Previous literature has drawn associations with the AEDs themselves reducing QOL (34) and AED cessation improving cognition (35). In our cohort 20 of the 57 patients had a trial of complete AED withdrawal, and of those, only three remained seizure free and off AEDs, this may reflect local practice of reducing to low dose single AED in preference to recommending complete withdrawal, the latter generally occurring only in patients who were seizure free and requesting to stop all AEDs.

Patients' subjective interpretation of their health seems to correlate with their clinical picture, with 14.7% reporting no change or a decrease in their QOL on their questionnaire responses with a similar percentage as those who class as Engel IV (Figure 2a). Although, these were not necessary the same individuals, as responses and case notes could not be linked due to questionnaires being anonymized at the start of data collection. Those completely seizure free reported a significant difference in their QOLIE-P31 compared to those not seizure free ($P<0.006$). Of the 19 patients who returned their questionnaire who were still experiencing seizures, 12 still described their QOL 'much improved' or 'very much improved' following surgery, demonstrating the importance of recording patient's opinions and QOL measures in addition to Engel scores.

Although a majority of patients reported an increase in QOL post-surgery, many burdens of their chronic disease including higher cognitive functioning persist. This may explain why our patients' employment levels post-surgery remain low. Of the 38 patients in whom we had records for both pre and post-surgery neuropsychometry testing, only 13% (5) had mild improvements to verbal memory. A majority showed similar performance or a mild reduction in verbal memory compared to pre-surgery testing. Age at surgery and duration of epilepsy are also likely factors in predicting post-operative employment. Career prospects have been shown to be optimal when

surgery is performed at a young age with minimal time between habitual seizure and referral (36). The median time of 24 years to surgery in our cohort was a likely factor in low rates of employment after surgery even if seizure free.

Despite nearly 50% of our cohort being seizure free at their most recent outpatient appointment, only 21% (7) were driving based on questionnaire responses. A previous systematic review found wide variation in driving status post-surgery (7-65%), age at surgery was a factor (37). National variation in transport links also likely contributes.

Previous studies have noted a wide range of visual field defects (VFD) (6-76%) following temporal lobectomy or selective mesial resection. One report found that of the nearly 75% who experienced VFD, 48% had driving-relevant VFD (38, 39). 40% of our total cohort were documented as having post-surgical VFD although the extent of the deficit and impact on driving was not recorded. Questionnaires responses suggested ongoing anxiety associated with driving. Many spent decades adapting their life to manage without the need for driving and there was a sentiment of not wanting to 'tempt fate'.

The goal of epilepsy surgery is to achieve long-term seizure freedom. The achievement of seizure freedom is not a static event. Previous studies have found a correlation between long term seizure freedom and absence of focal seizures with retained awareness in the first 2 post-operative years (12)(40). In our cohort, eight patients who were seizure free at one-year post-surgery experienced seizures in some capacity at five years post-surgery. Our measure of AED load showed a continued fall until at least eight years post-surgery. Had our follow up period been shorter, cases of relapse would

have remained unrecorded, and the extent of reduced AEDs would also have been missed, emphasizing the need for longer term follow up.

Given the benefits of timely epilepsy surgery, it is important to highlight the need to reduce the time taken to refer to epilepsy surgery. The reasons for delay are likely a combination of the need for better information amongst the neurology community and adequate resources. One study of 796 neurologists found over half would wait a year before a surgical referral in those suffering from refractory epilepsy, over 75% felt the greatest barrier was a lack of resources (41). Furthermore, the time to surgery after initial pre-surgical evaluation is important and steps in the surgery pathway need to be streamlined as far as possible.

Linking our surgical cohort to the SAIL database of routinely-collected health care data showed a clear reduction in hospital admissions as a marker of health care utilization post-surgery. This represents an additional cost saving when coupled with the reduction in AED costs.

Our study had limitations, mainly the retrospective data collection and the incomplete data capture. This could have introduced bias, e.g., unavailable clinical notes in those lost to follow-up, who perhaps had better seizure outcomes, subjective interpretation during clinical assessments, and those who returned questionnaires, with only a 40% response rate being biased toward those reporting improved (or otherwise QOL), or biased by their experience of epilepsy surgery. Trying to ascertain why some in our cohort failed to achieve seizure freedom is limited by sample size and retrospective review. Trying to establish causality as to which pre-surgical factors could be a marker to surgical failure remains challenging. We were also only able to link 60% of the patients with 10 years of their routinely-collected data mostly due to incomplete historic data and lack of linkage due to changes of addresses outside Wales. Nevertheless, we show significant changes in the factors we were able to measure and demonstrate this as a way forward for future studies of post-operative epilepsy surgery outcomes. **Finally, our cohort predominantly consisted of lesional temporal epilepsy cases with hippocampal sclerosis and those with other cortically based lesions. It is known that best surgical outcomes are seen in lesional temporal lobe cases and future studies are needed to address outcomes from more complex epilepsy surgical procedures (42).**

5.1 Conclusion

In summary, we demonstrate the demographics and benefits of epilepsy surgery in terms of seizure outcomes, quality of life and health care utilization. We, as elsewhere, note a long delay from diagnosis to surgery, and continued work is needed to improve this, in addition to continued monitoring of long-term outcomes after epilepsy surgery.

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Table and figure legends

Figure 1. The histological causes of the epilepsy in our cohort of 57 patients.

Figure 2. a). Post-operative outcomes at most recent outpatient clinic (median follow up 7 years) - Engel classification. (see appendix 1). **b)** Engle classification of patients at 1, 5 and 7-8 years after their surgery. **c)** The type and frequency of seizures, pre-surgery and one year after surgery. **d)** Type and frequency of seizures, against patient number and percentage at their last outpatient clinic.

Figure 3. Drug use per capita in the years following surgery. The number on the Y axis refers to the average anti-epileptic drug score per capita. AEDs were scaled, where 1 is the maximum dose of single drug as recommended by the British National formulary (March 2017). Patients scores were added together to give an overall number and per capita calculated.

Figure 4. Subjective QOL questionnaire responses ranging from one to 13 years post-surgery.

Figure 5. Box and whisker plot showing the difference in quality of life of those who achieved seizure freedom following surgery and those who did not.

Figure 6. Box and whisker plot of admission rates per 1,000 days for the five years before and after surgery. The median hospital admission rates were 9.84 per 1,000 patient days before surgery vs 3.89 per 1,000 patient days after surgery.

Figure 1.

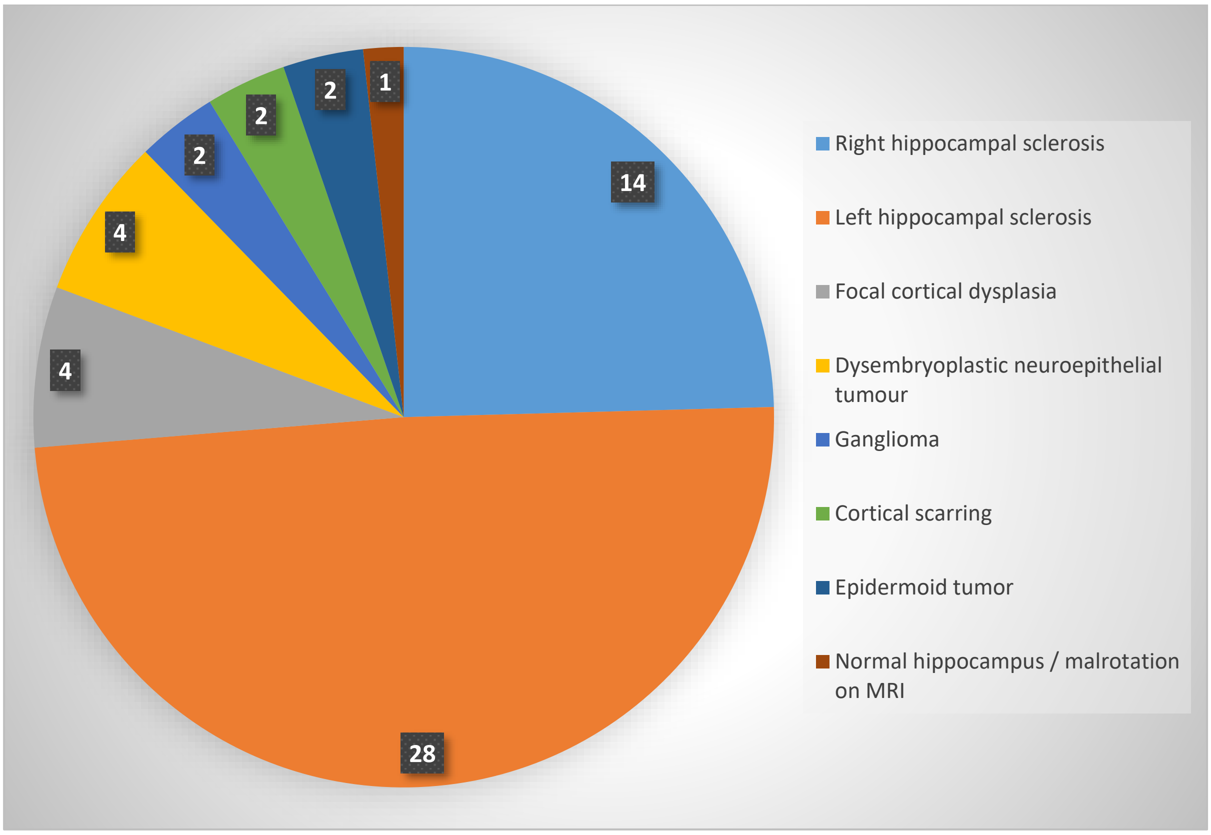

14
28
4
4
2
2
2
1
Right hippocampal sclerosis
Left hippocampal sclerosis
Focal cortical dysplasia
Dysembryoplastic neuroepithelial tumour
Ganglioma
Cortical scarring
Epidermoid tumor
Normal hippocampus / malrotation on MRI

Figure 2

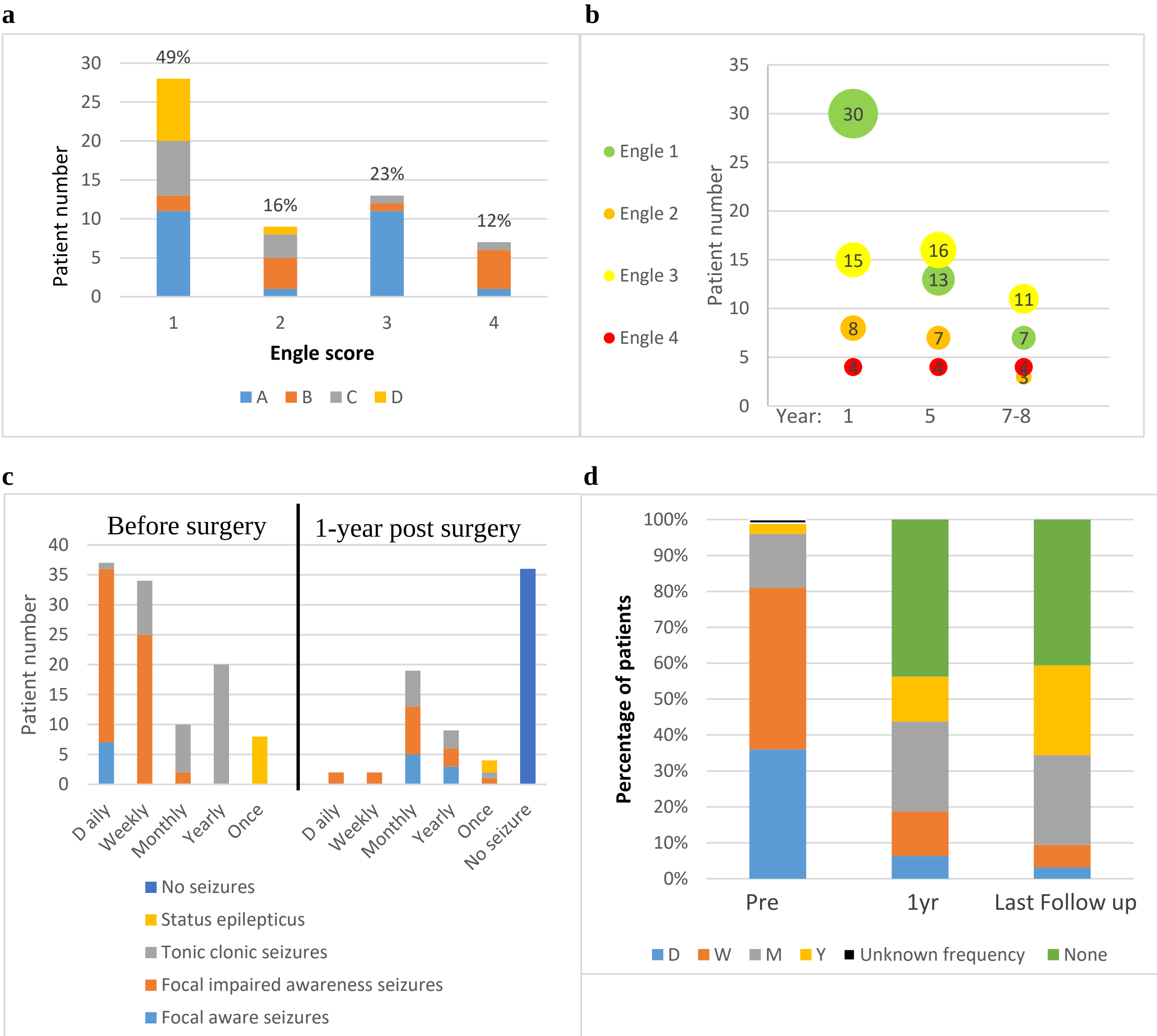

a
49%
16%
23%
12%
Patient number
Engle score
A B C D
b
Engle 1
Engle 2
Engle 3
Engle 4
Patient number
Year: 1 5 7-8
c
Before surgery
1-year post surgery
Patient number
Daily Weekly Monthly Yearly Once
Daily Weekly Monthly Yearly Once No seizure
No seizures
Status epilepticus
Tonic clonic seizures
Focal impaired awareness seizures
Focal aware seizures
d
Percentage of patients
Pre
1yr
Last Follow up
D W M Y Unknown frequency None

Figure 3.

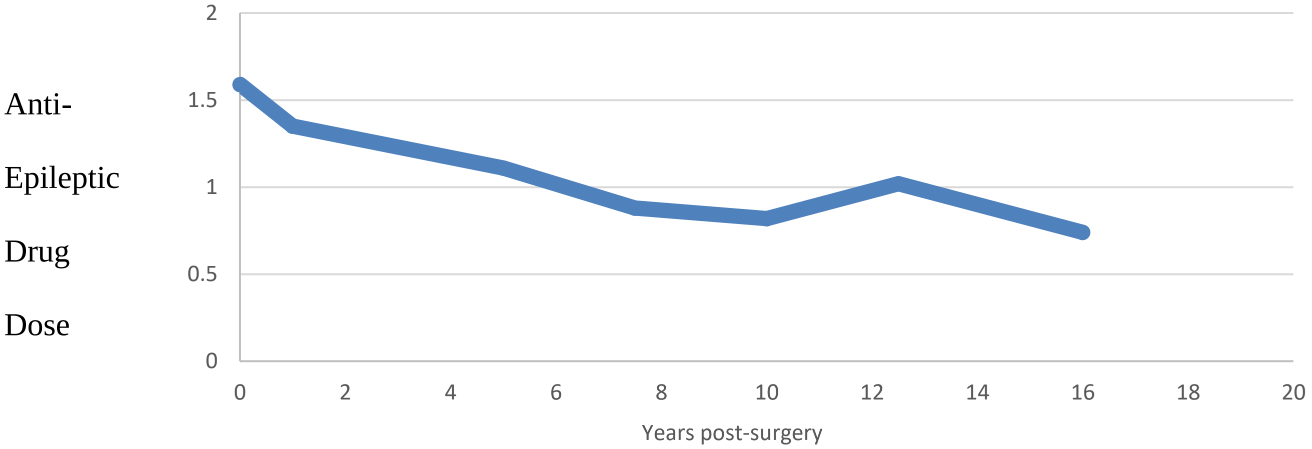


Figure 4.

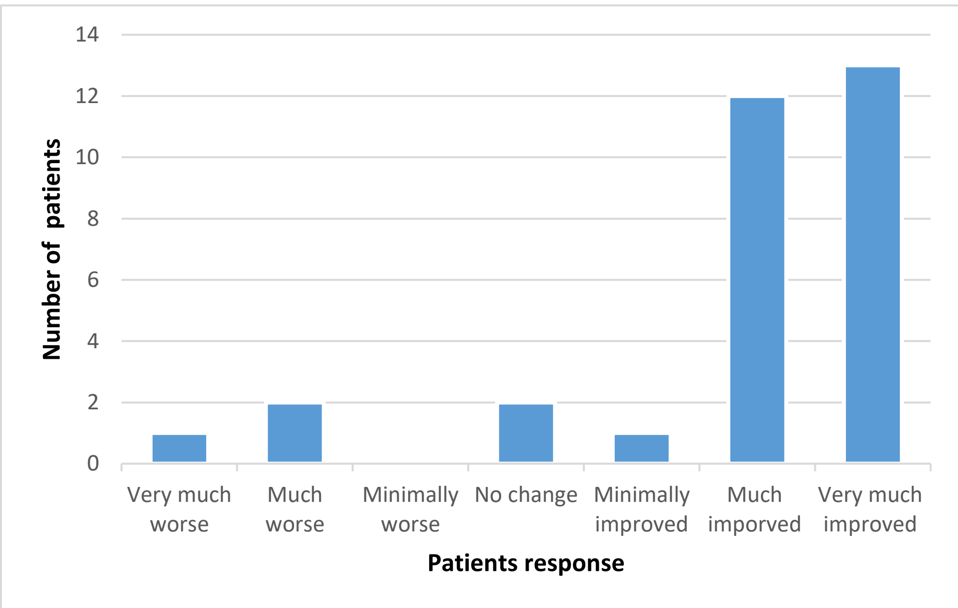


Figure 5.

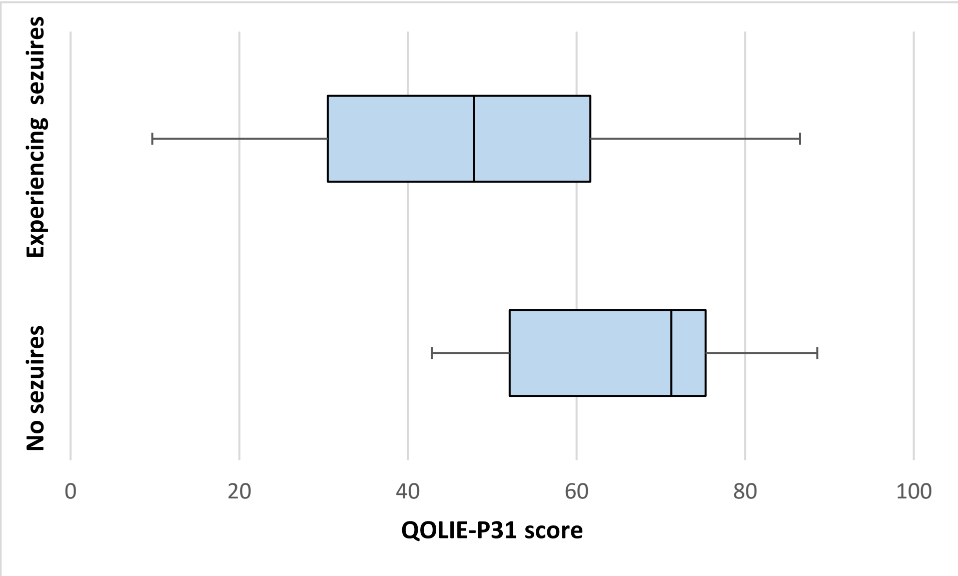
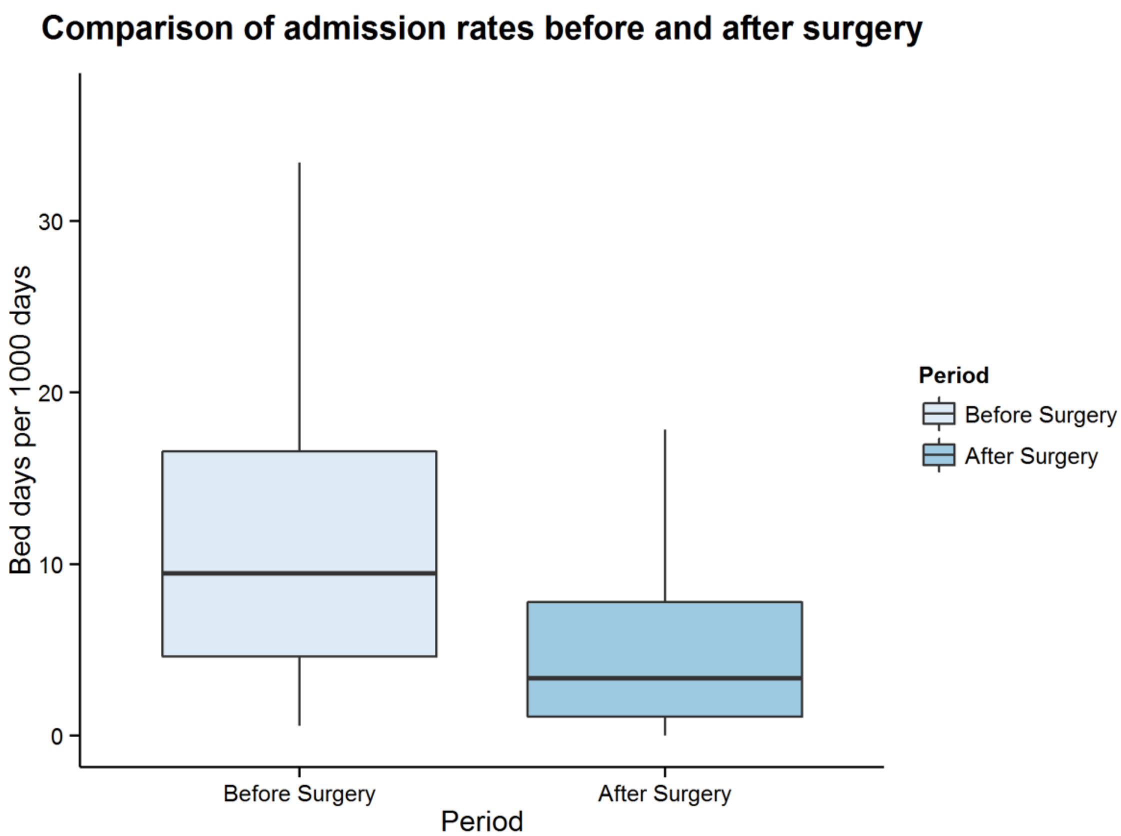


Figure 6.



Acknowledgements

This study makes use of anonymised data held in the Secure Anonymised Information Linkage (SAIL) system. We would like to acknowledge all the data providers who make anonymised data available for research. We thank our patients for their participation in the survey and support from the Wales Epilepsy Unit.

Appendix 1: Engel classification score.

Class I. Free from disabling seizures

A. Completely seizure free since surgery

B. Non disabling simple partial seizures only since surgery

C. Some disabling seizures after surgery, but free from disabling seizures for ≥2 years

D. Generalized convulsions w/AED discontinuation only

Class II. Rare disabling seizures (almost seizure free)

A. Initially free from disabling seizures, but still has rare seizures

B. Rare disabling seizures since surgery

C. Occasional disabling seizures since surgery, but rare seizures for the last 2 years

D. Nocturnal seizures only

Class III. Worthwhile improvement

A. Worthwhile seizure reduction

B. Prolonged seizure-free intervals amounting to >50% of follow-up period, but not <2 years

Class IV. No worthwhile improvement

A. Significant seizure reduction

B. No appreciable change

C. Seizures worse

Appendix 2: Patient questionnaire:

Service Evaluation of Epilepsy Surgery in Wales

Patient Questionnaire

We would be grateful if you could take a couple of minutes to answer this questionnaire. Your answers will help us evaluate and improve the current services available to people with epilepsy in Wales.

Please tell us your full name, date of birth and address:

Full name:

……………………………………………………………………………………

Date of birth:

……………………………………………………………………………………

Address:

……………………………………………………………………………………

When did you have surgery for your epilepsy?

……………………………………………………………………………………

Where did you have surgery for your epilepsy?

……………………………………………………………………………………

How old were you when you were diagnosed with epilepsy?

……………………………………………………………………………………

Are you right-handed or left-handed?

……………………………………………………………………………………

Epileptic Seizures

How frequent were your seizures before surgery?

- Every month
- Every week
- Every day

- Once or twice a year

Please tell us what kind of seizures these were:

………………………………………………………………………………………

How frequent were your seizures in the first year after surgery?

- Every month
- Every week
- Every day
- Once or twice a year
- Never

Please tell us what kind of seizures these were:

………………………………………………………………………………………

How frequent have your seizures been in the last year?

- Every month
- Every week
- Every day
- Once or twice a year
- Never

If ‘never’, please tell us when was the last time you had a seizure and describe what kind of seizure you had:

………………………………………………………………………………………

Antiepileptic Medication

If you can, please tell us the **number** and **names** of the medications you were taking for your epilepsy in the year **before** surgery:

………………………………………………………………………………………

If you can, please tell us the **number** and **names** of the medications you were taking for your epilepsy in the year **after** surgery:

………………………………………………………………………………………

What medications are you taking for your epilepsy now?

………………………………………………………………………………………

Did you have any complications following surgery for your epilepsy?

…………………………………………………………………………………………

Driving

Do you currently drive?

- Yes
- No

If you answered 'yes' to the previous question or have previously driven, please tell us how soon after your operation were you able to drive?

……………………………………………………………………………....

Employment/Education

What is your current employment status?

- Full-time employment
- Part-time employment
- Unemployed
- In higher education

Please tell us your job and how your career has been influenced by your epilepsy

……………………………………………………………………………………

Global Impression of Change and Quality of Life

Over the past year, how have you felt compared to before you had surgery for your epilepsy? (please tick the box that best describes your condition):

- Very much improved
- Much improved
- Minimally improved
- No change
- Minimally worse
- Much worse
- Very much worse

How has the quality of your life changed since you had surgery for your epilepsy?

- Very much improved
- Much improved
- Minimally improved
- No change
- Minimally worse
- Much worse
- Very much worse

Is there anything else you would like to tell us?

………………………………………………………………………………

If you are happy for your comments to be included (anonymously) in any publication, please indicate so here:

- I am happy for my comments to be used in any publication

- I do want my comments to be used in any final publication

Are you happy for us to contact you by telephone if further information is required?

- Yes
- No

My preferred phone number is

…………………………………………………………..

and preferred contact time

……………………………………………………………...

Thank you for taking the time to answer and return this questionnaire. We would appreciate if you could also answer the ‘Quality of Life in Epilepsy’ questionnaire. Your responses will be anonymised and will help us to review the outcomes of epilepsy surgery.

Appendix 3: QOLIE 31-P