Title:

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

Authors:

Ben Kansu1,2, William O Pickrell3, Arron S Lacey3,4, Ffion Edwards3, Georgiana Samolia5, Mark I Rees3,6, Liam Gray1,7, Khalid Hamandi1,7\*

Author affiliations

1. The Wales Epilepsy Unit, University Hospital Wales, Cardiff, CF14 4XW

2. School of Medicine, UHW Main Building, Heath Park, Cardiff, CF14 4XN

3. Neurology and Molecular Neuroscience Group, Institute of Life Science, Swansea University School of Medicine, Swansea University, Swansea SA2 8PP

4. Health Data Research UK, Data Science Building, Swansea University Medical School, Swansea University, Swansea

5.

6. Faculty of Medicine and Health, University of Sydney, Sydney, Australia.

7.

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**Highlights:**

* **Previous studies have shown good outcomes after short-term follow up, mostly less than five years**
* **We show similar outcomes with longer follow up (Average follow up 7 years)**
* **At last follow up, 49% of patients were seizure free with 88% having at least a worthwhile improvement in seizure frequency**
* **There was a significant increase in quality of life (QOLIE-31-P) post surgery**
* **There was a significant reduction in hospital admissions for all causes 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.

,; ,; ,sclerosis; , ; ,; ,; VNS, Vagal nerve simulator.

**Key words:**

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

**1.1 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, or drug resistant epilepsy (DRE) (3). DRE is 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 curative treatment option in selected cases, with a strong evidence base for reducing or halting seizures and reducing AED dependence, along with beneficial outcomes on quality of life (QOL) (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 to patients, carers and treating physicians. This time to surgery likely 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.

**2.1 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. Patients were excluded when the primary aim of surgery was tumor resection or those undergoing vagus nerve stilumator (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)]. We determined changes in seizure frequency and character, time to surgery from initial diagnosis, changes in epilepsy drugs 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 out-patient appointment, where one is the best outcome and four the worst, with subcategories for each class (appendix 1 – supplementary materials). 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 (24). 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) (24).

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(25)]. 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(25)).

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(26, 27). 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.

**3.1 Results**

We identified 406 cases as having epilepsy and neurosurgery, 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. 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) |
| Resective surgery for a space occupying lesion | 10 |

Table 1: Type of surgical procedure undertaken.

49 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 time between onset of habitual seizures (median of one years of age) and surgery being 24 years (range 2­–56). Median duration of follow up after surgery was seven years (range 1–19). Lateralisation 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).

**3.2 Post-operative seizure outcomes**

49% 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) (11). A more detailed breakdown of seizure type and frequency before and at one year following surgery was also determined (figure 2b), and of seizure type and frequency at long term follow up (figure 2c).

**3.3 Post-operative morbidity outcomes**

Six of the 57 patients suffered surgical site infections with three requiring cranioplasty and one requiring an ITU admission. Three patients experienced de novo 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. One other patient attempted suicide with no previous psychiatric history. 23 patients experienced at least mild visual impairment on formal testing.

**3.4 Anti-epileptic drug usage**

Patient follow up data reduced with increasing time post-surgery, and therefore, total drug consumption was calculated per capita (Figure 4). 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. Of the three seizure-free patients, two stopped their AEDs, having previously taken 1500mg of levetiracetam and 300mg of pregabalin respectively. 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 carbamazapine. After a second attempt at medication reduction 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.

**3.5 Postal survey**

Of the 84 patients identified, 34 (40%) completed questionnaires. Results are summarized in table 2.

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

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

The seven patients who returned to drive did so 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.

**3.6 QOLIE-P31 questionnaire**

Four responses were excluded due to incomplete responses to the questions. The remaining 30 scores were calculated. 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).

**3.7 Routinely-Collected 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.

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 48% 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. QOLIE-P31 scores showed a significant difference in quality of life between those who achieved seizure freedom and those who did not. There was close correlation between seizure outcomes, subjective quality of life questionnaire responses and QOLIE-P31 scores. The majority of patients responded that undergoing epilepsy surgery was a positive outcome for them. We found a measurable reduction in the total AED dosing following surgery, 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 anonymised hospital data before and after surgery. There was a significant reduction in all hospital stays after surgery for this cohort.

The Engel classification is a commonly used outcome measure in epilepsy surgery. However, this does not capture changes in seizure type or severity. 14% of patients showed no improvement in seizure frequency (class IV). Nevertheless the seizure severity improved, for example, 38 of the 57 patients experienced at least yearly tonic-clonic seizure (TCS) pre-surgery in comparison to eight at the most recent outpatient visit.

There were significantly more left HS resections when compared to right HS resections. This has also been reported by other centers. (28) The reasons are unclear, and we do not know the overall prevalence of all HS in our epilepsy population. A higher prevalence of left compared to right HS has been reported (29, 30). We postulate that left HS could be more likely to come to surgery because of more debilitating seizures (with loss of awareness), compared to right HS (31).

Previous studies have reported AED use and seizure freedom (21, 32), we found it additionally helpful to develop a measure of AED burden as an outcome measure.

There was 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 (33) and AED cessation improving cognition (34). 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 minimal acceptable dose in preference to complete withdrawal.

Patients’ subjective interpretation of their health seems to correlate with their clinical picture, with 14.7% reporting no change or a decrease in their questionnaire responses with a similar percentage as those who class as Engel IV (Figure 2a), although these were not necessary the same individuals. Those completely seizure free reported a significant difference (P<0.006) in their QOLIE-P31. 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.

The goal of epilepsy surgery is to achieve long-term seizure freedom. The achievement of seizure freedom is not a static event. In our cohort, eight patients who were seizure free at one-year post surgery experienced seizures in some capacity at five years post-surgery, and AED load continued to fall until at least eight years post-surgery.

Our study had limitations, mainly the retrospective data collection and the incomplete data capture. This could have introduced bias into the finding, eg 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.

**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.**

**Figure 2.** **a)**. Post-operative outcomes at most recent outpatient clinic - Engel classification. 1, Class 1 (Free from disabling seizures); 2, Class 2, Rare disabling seizures; 3, Class 3 (Worthwhile improvement); 4, Class 4 (No worthwhile improvement). Letters represent subclasses of categorization (see appendix 3), **b)** The type and frequency of seizures, pre surgery and one year after surgery. D, daily; W, weekly; M, monthly; Y, yearly; O, once – the patient had one seizure acutely post-surgery. **Figure 2c:** Type and frequency of seizures, against patient number and percentage at their last outpatient clinic. **2d.**  self-reported seizure frequency (n = 34).

**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.**

**Figure 2a**

Number of patients

Engel score

**Figure 2b**

**Pre-surgery 1 year post-surgery**

Number of patients

**Figure 2c**

Number of patients

Frequency of seizures

**Figure 2d**

Percentage of patients

**Figure 3.**

Years post-surgery

Anti-Epileptic

Drug

Dose

Per

capita

**Figure 4.**

Number of patients

**Figure 5.**

Experiencing seizures

No seizures

QOLIE-P31 score

**Figure 6.**

**Acknowledgements**

**BRAIN**

**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**

**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 |

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| **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