CHAPTER 7

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Is epilepsy surgery utilized to its full extent?

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Abstract

It has been stated that epilepsy surgery as a treatment is underutilized. In two random samples of epilepsy patients, one from a secondary and one from a tertiary epilepsy facility, we established how many patients should have been and were actually referred to the Dutch national taskforce for presurgical evaluation.

Using national guidelines for referral, of 578 evaluated patients with epilepsy, 95 patients (16%) should have been referred for presurgical evaluation but only 22 (4%) were actually referred. An expert panel, which reviewed clinical data from the 73 cases that were not referred, thought that 4 of these patients (5%) were potential candidates for presurgical evaluation and that diagnostic testing was insufficient in another 12 (16%). Our results show that, in the Netherlands, 1.3 to 2.4 times as many patients treated in secondary care should be referred for presurgical evaluation as were actually referred and 1.1 to 1.4 times as many patients treated in tertiary care.

We confirm that epilepsy surgery is underutilized in the Netherlands. Neurologists should be more aware of current guidelines, make better use of available non-invasive diagnostic tests, and discuss surgery as treatment option with their patients with drug-resistant epilepsy.

Introduction

In 2001, Jerome Engel jr. stated that epilepsy surgery in patients with drug-resistant focal epilepsy is one of the most neglected successful treatments worldwide.[15] The interval between onset of seizures and epilepsy surgery is 18.8 years on average,[133] whereas guidelines already advise screening for epilepsy surgery when patients have persistent seizures after two consecutive years of medical treatment and when two or three first-line antiepileptic drugs have failed.[13;134;135] On the basis of this information, we investigated whether epilepsy surgery is underutilized in the Netherlands and, if so, sought , to quantify the magnitude of the problem and identify reasons for underutilization.

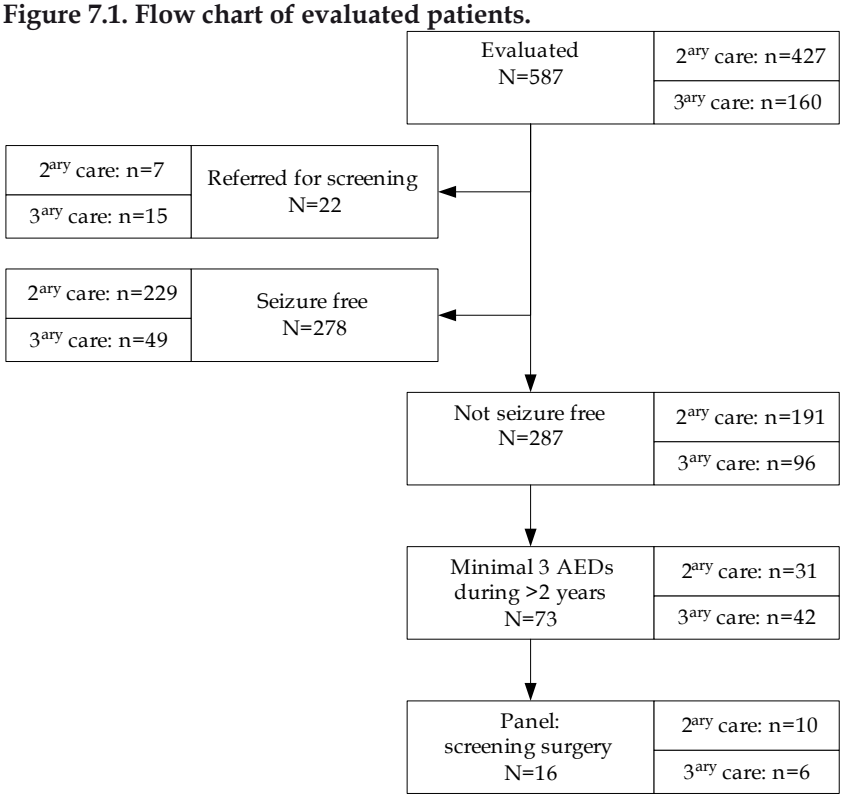
Methods

We collected two samples of adult patients who were diagnosed with, and medically treated for, epilepsy, one from a general hospital and one from a tertiary epilepsy clinic. In each center, we took a random sample of the files of patients treated for epilepsy in 2005, excluding patients who had been referred for presurgical evaluation and patients who had been seizure free for at least six months at the time of their last visit. The files of patients who had not been previously referred for presurgical evaluation, who had not been seizure free, and who had been treated for at least two consecutive years with three or more antiepileptic drugs were evaluated by an expert panel of two independent epileptologists (FL and PV) who are participants in the national presurgical evaluation program for epilepsy surgery. The expert panel determined whether patients were candidates for the presurgical evaluation program or whether they were potential candidates, i.e., whether additional diagnostic tests (MRI according to special epilepsy protocol, video EEG monitoring) were needed to determine candidacy for presurgical evaluation. The attending physicians of these potential candidates were asked why presurgical evaluation had not been considered.

Results

Figure 7.1 shows the flow chart of the random sample of 587 patients, 427 from the general hospital and 160 from the epilepsy center. Of these, 22 patients (4%) had previously been referred to the presurgical evaluation program and 278 patients (47%) had been seizure free for at least six months. In the general hospital, 191 of 427 patients (45%) had not been seizure free and in the epilepsy center 96 of 160 patients (60%). Of these 287 (191+96) patients, 73 (25%) had had seizures for at least two years and had been treated in this period with at least three antiepileptic drugs. The expert panel evaluated these 73 patients and concluded that 4 (2 in secondary and 2 in tertiary care) were candidates for presurgical evaluation. Another 12 patients were considered potential candidates, pending relevant additional tests.

Figure 7.1. Flow chart of evaluated patients.



The other 57 (78% of the 73) patients were ineligible for surgery due to type of epilepsy (40%), low seizure frequency or only nocturnal seizures (32%), contraindications (18%), age (7%), or rejection of surgery by the patient (3%).

The attending physicians of the 16 (4+12) patients identified as candidates or potential candidates (22% of 73, 3% of 578) for presurgical evaluation had not considered the possibility of such an evaluation for their patients. The mean time since failure of a third drug was 5.7 years (standard deviation 5.7; median 4.3; range 0.3 to 19.6) and the mean time since the onset of seizures was 18.9 years (standard deviation 12.3; median 18.1, range 5.1 to 47.6). In 7 patients, the physicians considered the burden of seizures to be low and they had not discussed surgery with the patient. Another 6 patients – all treated in secondary care - had been referred to tertiary care in the past, but the issue of epilepsy surgery had not been raised. No reasons were given for the other three patients.

In the sample of patients treated in secondary care, 7 patients had previously been referred to presurgical evaluation, and according to the expert evaluation 10 more patients (2 candidates and another 8 potential candidates) were eligible for referral. This means that referral should be considered 1.3 to 2.4 times more often than is currently the case in secondary care; i.e., in (7+2)/7 to (7+10)/7 times as many patients. In tertiary care, 15 patients had previously been referred and according to the expert evaluation 6 more patients (2 candidates and 4 potential candidates) were eligible for referral, leading to (15+2)/15 to (15+6)/15 or 1.1 to 1.4 times as many patients who should be referred for presurgical evaluation than is currently the case. Overall, we found that presurgical evaluation was needed in 26 (22 previously referred + 4 candidates) to 38 (22 previously referred + 16 potential candidates) of 578 patients, or in 4% to 7% of our patient sample, which is slightly higher than the estimate of 3% by Lathoo et al. for the UK.[136]

Conclusion

In interpreting our results, it is apparent that there is a "pool" of patients that has not been referred for presurgical evaluation during the preceding years, even though such referral would seem appropriate. For this reason, it is not possible to give an indication of the expected increase in the number of patients that should be referred for presurgical evaluation for epilepsy surgery.

We confirm that there is a substantial underutilization of epilepsy surgery and that epilepsy surgery as a treatment should receive more emphasis in secondary as well as tertiary care. Physicians should adhere more strictly to current guidelines for referral to the presurgical evaluation program for epilepsy surgery and make better use of available non-invasive diagnostic techniques. Moreover, they should always discuss surgery with their patients if seizures persist after at least 2 years of medical treatment and failure of a third antiepileptic drug.