Epilepsy Surgery: Factors That Affect Patient Decision-Making in Choosing or Deferring a Procedure

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Surgical resection for well-selected patients with refractory epilepsy provides seizure freedom approximately two-thirds of the time. Despite this, many good candidates for surgery, after a presurgical workup, ultimately do not consent to a procedure. The reasons why patients decline potentially effective surgery are not completely understood. We explored the socio cultural, medical, personal, and psychological differences between candidates who chose (n = 23) and those who declined surgical intervention (n = 9). We created a novel questionnaire addressing a range of possible factors important in patient decision making. We found that patients who declined surgery were less bothered by their epilepsy (despite comparable severity), more anxious about surgery, and less likely to listen to their doctors (and others) and had more comorbid psychiatric disease. Patients who chose surgery were more embarrassed by their seizures, more interested in being “seizure-free”, and less anxious about specific aspects of surgery. Patient attitudes, beliefs, and anxiety serve as barriers to ideal care. These results can provide opportunities for education, treatment, and intervention. Additionally, patients who fit a profile of someone who is likely to defer surgery may not be appropriate for risky and expensive presurgical testing.

1. Introduction

Approximately one-third of patients with epilepsy will not attain seizure freedom through medications alone. If patients are not free of seizures after trying two different antiepileptic drugs (AEDs), their chance of relief from a third is between five and ten percent [1].

After multiple AEDs have failed, physicians often propose resective epilepsy surgery. In 2001, a randomized, controlled trial comparing temporal lobectomy to continued pharmacologic therapy found that 58% of the surgical group was seizure-free at one year, compared with 8% in the pharmacologic group [2]. These results have been replicated, and meta-analyses show that approximately two-thirds of patients are seizure-free at long-term followup after a temporal lobe resection [3, 4].

There are more candidates for epilepsy surgery than those who actually receive a procedure. There are many factors involved in this disparity: patients’ lack of access to comprehensive epilepsy surgery centers, low levels of referrals by physicians, and an unclear medical consensus regarding the appropriateness of recommending surgery versus continued AED treatment [5]. Even when referred to an epilepsy center, some good candidates for epilepsy surgery decline the procedure and choose to remain on pharmacologic therapy, even after undergoing a tedious and expensive presurgical evaluation. Patients’ attitudes towards surgical intervention likely affect procedure rates although the literature on this barrier is limited.

Swarztrauber et al. [6] held focus groups to ask patients questions about their views of different treatments for
intractable epilepsy, including surgery. The authors found many patients opted against surgery due to a general mistrust of brain surgery, negative medical provider opinions of surgery, lack of correct information about the success rates and risks, and poor patient-physician relationships. We conducted this study to further explore how sociocultural, medical, personal, and neuropsychological factors are associated with patients’ decision making regarding surgery.

We studied the attitudes, priorities, and beliefs of patients who were offered a temporal or extratemporal resection and compared the responses of those who chose the surgery (surgical group) to those who decided against it (nonsurgical group). We used a survey to collect patients’ opinions and carried out a chart review of relevant medical information. Our goal was to determine what issues should be addressed with these patients throughout the process of presurgical evaluation to prevent unnecessary testing and help good candidates make appropriate, evidence-based decisions.

2. Materials and Methods

2.1. Participants. We recruited patients from the Penn Epilepsy Center at the Hospital of the University of Pennsylvania over a 12-month interval. Inclusion criteria were as follows: all patients had to be 18 years or older, have intractable partial-onset epilepsy, had undergone a presurgical workup including a stay in the epilepsy monitoring unit, an MRI of the brain, an FDG-PET of the brain, neuropsychological testing specific to epilepsy, and were offered either resective epilepsy or invasive electrocorticography with a plan of likely resection at explant of intracranial electrodes. All patients provided informed consent. All study methods were approved by the hospital’s IRB and in accordance with HIPAA regulations.

While we aimed for an equal number of participants in the surgical and nonsurgical groups, there were challenges recruiting in the nonsurgical group, such as being unable to contact patients or follow up initial conversations by phone (detailed further in the discussion). We initially contacted 41 patients in total, 26 surgical patients and 15 nonsurgical patients. Thirty-three participated, for a participation rate of 80.5%. When we attempted to follow up our initial conversation with eight patients, we were unable to contact them further. Twenty-three of the respondents were in the surgical group, and ten were in the nonsurgical group (One patient who refused surgery had to be retroactively excluded from the data analysis due to a lack of some pre-surgical tests, so all analysis was done with \( n = 9 \)).

Patients were invited to participate either by phone or directly after their regular clinic appointment. Whether conducted via telephone or in person, the study survey lasted approximately 30 minutes (range: 15–60 minutes). Twenty-one surveys were completed in person (100% response rate), and 12 surveys were completed over the phone (60% response rate).

2.2. The Questionnaire. Due to the lack of survey instruments designed for the purpose of assessing epilepsy patients’ attitudes towards surgery, we created a novel questionnaire to gain this subjective information. (See Appendix for the questionnaire).

We also collected demographic information: age, level of education, place of birth, marital status, self-reported ethnicity, number of children, employment status, disability status, and other surgical histories. We asked about epilepsy characteristics: age at seizure onset, duration of epilepsy, number of current AEDs, number of previous AEDs, and seizure frequency.

Patients were presented with a list of 36 potentially important factors to their decision-making process and rated each on a Likert scale from 0 (not important) to 4 (most important) or “Not Applicable.” Each factor fell under one of the following themes:

(i) Details of Epilepsy,
(ii) Effects of Epilepsy,
(iii) Other People/Group’s Beliefs,
(iv) Surgical Fears,
(v) Medication Effects,
(vi) Hopes After Surgery,
(vii) Alternative Treatment Options,
(viii) Personal Beliefs About the Surgery,
(ix) Doctor’s Information About Surgery.

For “Details of Epilepsy,” we asked patients to consider how long they had been living with epilepsy and the frequency and severity of their seizures. “Effects of Epilepsy” factors included work limitations from seizures, stigma of having epilepsy, embarrassment from seizures in public, fear of death from seizures, fear of physical injury from seizures, the desire/need to be seizure-free, and access to disability benefits. “Other People/Group’s Beliefs” included the opinions of family members and friends and the effect of faith and religion. “Surgical Fears” included fear of surgery in general, comfort of surgery in general, fear of being put under anesthesia, fear of not waking up after the procedure, fear of complications during the procedure, fear of resulting memory loss and/or cognitive decline, and concerns that other health conditions may impact the surgery. “Medication Effects” included the number of medications taken prior to surgery (or proposed surgery) and the physical and mental side effects of antiepileptic medications. “Hopes After Surgery” addressed career opportunities and the future ability to drive. “Alternative Treatment Options” included availability of the vagal nerve stimulator and future devices such as deep brain stimulation or responsive brain stimulation, which may reach the marketplace in the next several years [7]. “Personal Beliefs About the Surgery” factors were the personal belief that the surgery would work, knowledge of others’ successes or failures with a procedure, and the extent to which surgery has been proven scientifically. “Doctor’s Information About Surgery” factors were the chances of success, risks of complications during surgery, and the risks of disability after surgery; all quoted to the patient by the physician or neurosurgeon. Finally, patients were invited to
list any factors that influenced their decision but were not
covered in the survey.

Last, we asked participants where they got most informa-
tion about the surgical procedure and who was most influ-
ential in their decision. The available choices were epilepsy
doctor, neurosurgeon, another member of the epilepsy center
team, informational DVD, another patient who had the
procedure, family or friends, or other.

2.3. Chart Review. We conducted a chart review to objec-
tively gather the following information: epilepsy history and
diagnosis, drug and alcohol history, cause of epilepsy, type of
seizures, and comorbid psychiatric disorders.

2.4. Statistical Analysis. Ordinal data was compared using
the Wilcoxon rank-sum test. Categorical data was compared
using Fisher’s test. P values of less than 0.05 were considered
indicative of significant group differences.

3. Results

3.1. Demographics. Tables 1 and 2 report demographic char-
acteristics across our surgical and nonsurgical groups. There
was a significant difference in age (mean surgical age = 43,
mean nonsurgical age = 54, P = 0.046), self-reported
ethnicity (P = 0.015), and comorbid psychiatric disorders
(P = 0.005). Several other variables did not reach statistical
significance.

3.2. Factors Affecting the Surgical Decision. For our analysis,
we grouped together responses of “Not Applicable” and “Not
Important.” We assigned both responses to our 36 factors a
score of 0 in our calculations. Table 3 reports the means and
standard deviations for the individual factors and themes.

Twelve factors revealed significant differences between
the two groups: frequency and severity of seizures (P = 0.002),
length of time with seizures (P = 0.031), stigma of
having epilepsy (P = 0.022), embarrassment from seizures in
public (P = 0.037), need/desire to be seizure-free (P = 0.000),
frustration with epilepsy (P = 0.000), general comfort with
surgery (P = 0.019), fear of surgery in general (P = 0.005),
fear of complications during surgery (P = 0.002), concerns
that my other health conditions may impact surgery (P = 0.045),
chances of success quoted to me by my doctor (P = 0.040), and
my belief that surgery would work (P = 0.002).

3.3. Patient Sources of Information and Influences. Table 4
reports patients’ sources of information about surgery, and
identifies the most influential individual in patients’ decision-
making process. Options that were not chosen by any patients
were not included in the table and frequently given answers
by patients who chose “Other” were included. Patients were
allowed to choose multiple answers for each question.

The majority of patients identified their epilepsy doctor
as the main source of information (n = 28). Other common
sources were the neurosurgeon (n = 8) and the Internet (n
= 6). The majority of patients also said their epilepsy doctor
was the most influential individual in their decision (n = 18).

Other important influences were the neurosurgeon (n = 8),
themselves (n = 8), family and friends (n = 7), and a former
patient (n = 1).

Though not significant, there were interesting trends in
the patients’ responses. Surgical patients were more likely
than nonsurgical patients to report that they gained most
of their information from the Internet (27.1% versus 11.1%),
nurosurgeon (34.8% versus 0%), or epilepsy doctor (52.2%
versus 33.3%). Nonsurgical patients were more likely than
surgical patients to select “myself” as the most influential
individual (55.6% versus 13%).

4. Discussion

This study was an exploratory/hypothesis generating study
to determine why some candidates for epilepsy surgery refuse
surgery. We had a small sample size and created a new
questionnaire specifically for this study; these results should
be viewed as first step; further research should be done to
explore the reasons behind these differences. We surmise
that refusal of recommended epilepsy surgery is a more
widespread problem than most clinicians are aware.

The first finding from our study was that patients who
completed a presurgical evaluation but chose against surgery
are often difficult to contact and/or unwilling to discuss
their decisions. We aimed for approximately 25 participants
in each group but were unable to complete the interview
with more than 9 nonsurgical patients. We found they often
had nonworking phone numbers listed with the hospital,
they were not responsive to voicemails or letters, and if we
successfully made contact and they agreed to participate, they
would miss phone and clinic appointments. As a result, we
were only able to talk to patients who had recently made a
decision, usually at their clinic appointments.

Carlson et al. also noticed that in their cohort of surgical
candidates many did not progress to surgery [8]. With some
findings comparable to ours they found that 21% of their
surgical candidates declined surgery, 16% had no identifiable
reason, and 25% were lost to followup.

4.1. Demographics. Looking at our study population, the
surgical and nonsurgical groups differed in age, AED expo-
sure, ethnicity, and comorbid psychiatric disorders. We
also found a difference in self-reported ethnicity between
groups—only 8.7% of the surgical group were African
American, compared with 44.4% of the nonsurgical group.
Swarztrauber et al. (2003) found that African American
patients were less likely to opt for surgery, and while our study
does not indicate causation, this difference was significant.
Lastly, nonsurgical patients had a much higher prevalence
of psychiatric disorders, excluding depression (which was
equally prevalent between groups). Almost half the non-
surgical group had severe anxiety, while only 4.4% of the
surgical group did. Perhaps this presence of anxiety was
affecting patients’ decisions. Interestingly, seizure types and
frequency were not different between groups, indicating
that the nonsurgical group was not strongly influenced by
relatively less frequent or disruptive seizures. Although doses
### Table 1: Demographic characteristics of participants.

|                                | Surgical group (n = 23) | Nonsurgical group (n = 9) | P value |
|--------------------------------|-------------------------|----------------------------|---------|
| **Age (years)**                |                         |                            |         |
| Median (IQR)                   | 43 (32–47)              | 54 (42–56)                 | 0.046   |
| **Education (years)**          |                         |                            |         |
| Median (IQR)                   | 14 (12–16)              | 12 (12–14)                 | 0.163   |
| **Birthplace**                 |                         |                            | 1.000   |
| NJ                             | 2 (8.7%)                | 0 (0%)                     |         |
| PA                             | 18 (78.3%)              | 8 (88.9%)                  |         |
| Other in the USA               | 2 (8.7%)                | 1 (11.1%)                  |         |
| Outside the USA                | 1 (4.3%)                | 0 (0%)                     |         |
| **Current location**           |                         |                            | 1.000   |
| NJ                             | 2 (8.7%)                | 1 (11.1%)                  |         |
| PA                             | 21 (91.3%)              | 8 (88.9%)                  |         |
| **Marital status**             |                         |                            | 1.000   |
| Single                         | 9 (39.1%)               | 4 (44.4%)                  |         |
| Married                        | 12 (52.2%)              | 5 (55.6%)                  |         |
| Divorced                       | 2 (8.7%)                | 0 (0%)                     |         |
| **Children**                   |                         |                            | 1.000   |
| No                             | 11 (47.8%)              | 4 (44.4%)                  |         |
| Yes                            | 12 (52.2%)              | 5 (55.6%)                  |         |
| **Self-reported ethnicity**    |                         |                            | 0.016   |
| White                          | 20 (87.0%)              | 4 (44.4%)                  |         |
| Black                          | 2 (8.7%)                | 4 (44.4%)                  |         |
| Indian                         | 1 (4.3%)                | 0 (0%)                     |         |
| Hispanic                       | 0 (0%)                  | 1 (11.1%)                  |         |
| **Currently employed**         |                         |                            | 0.243   |
| No                             | 9 (39.1%)               | 6 (66.7%)                  |         |
| Yes                            | 14 (60.9%)              | 3 (33.3%)                  |         |
| **On social security disability benefits** |                   |                            | 0.109   |
| No                             | 16 (69.6%)              | 3 (33.3%)                  |         |
| Yes                            | 7 (30.4%)               | 6 (66.7%)                  |         |
| **Comorbid depression**        |                         |                            | 0.694   |
| No                             | 11 (47.8%)              | 3 (33.3%)                  |         |
| Yes                            | 12 (52.2%)              | 6 (66.7%)                  |         |
| **Other comorbid psychiatric disorders** |                 |                            | 0.005   |
| None                           | 19 (82.6%)              | 4 (44.4%)                  |         |
| Anxiety                        | 1 (4.4%)                | 4 (44.4%)                  |         |
| Mood disorder                  | 1 (4.4%)                | 1 (11.1%)                  |         |
| ADHD                           | 2 (8.7%)                | 0 (0%)                     |         |
| **History of alcohol or illegal drug use** |                   |                            | 1.000   |
| No                             | 22 (95.6%)              | 9 (100%)                   |         |
| Yes                            | 1 (4.4%)                | 0 (0%)                     |         |
| **History of smoking cigarettes** |                        |                            | 1.000   |
| No                             | 19 (82.6%)              | 7 (77.8%)                  |         |
| Yes                            | 4 (17.4%)               | 2 (22.2%)                  |         |
| **Prior surgical history**     |                         |                            | 0.249   |
| No                             | 11 (47.8%)              | 2 (22.2%)                  |         |
| Yes                            | 12 (52.2%)              | 7 (77.8%)                  |         |
| **Prior bad surgical experience** |                        |                            | 1.000   |
| No                             | 20 (87.0%)              | 8 (88.9%)                  |         |
| Yes                            | 3 (13.0%)               | 1 (11.1%)                  |         |

Ordinal data was compared using the Wilcoxon rank-sum test. Categorical data was compared using Fischer's test. P values <0.05 considered significant. *12 years education = high school graduate.
Table 2: Epilepsy characteristics of participants.

|                          | Surgical group (n = 23) | Nonsurgical group (n = 9) | P value |
|--------------------------|-------------------------|---------------------------|---------|
| Total years with seizures (years) | Median (IQR)            |                           |         |
|                          | 11 (9–21)               | 14 (10–35)               | 0.487   |
| Age at onset of seizures (years) | Median (IQR)            |                           |         |
|                          | 22 (13–26)              | 21 (14–44)               | 0.425   |
| Years since procedure or decision | Median (IQR)            |                           |         |
|                          | 4 (2–7)                 | 1 (1-1)                  | 0.000   |
| Current number of AEDs being taken | Median (IQR)            |                           |         |
|                          | 1 (1-2)                 | 2 (2-3)                  | 0.082   |
| Total AEDs tried until procedure or decision | Median (IQR)            |                           |         |
|                          | 5 (3–6)                 | 6 (5–7)                  | 0.056   |
| Seizure frequency (per month) |                         |                           | 0.287   |
| 1–3                      | 6 (26.1%)               | 4 (44.4%)                |         |
| 4–9                      | 5 (21.7%)               | 2 (22.2%)                |         |
| 10+                      | 12 (52.2%)              | 3 (33.3%)                |         |
| Types of seizures       |                         |                           | 0.327   |
| Complex partial          | 12 (52.2%)              | 2 (22.2%)                |         |
| Generalized tonic clonic (GTC) | 0 (0%)                | 0 (0%)                   |         |
| Simple partial and complex partial | 2 (8.7%)              | 2 (22.2%)                |         |
| Simple partial and GTC   | 1 (4.3%)                | 1 (11.1%)                |         |
| Complex partial and GTC  | 6 (26.1%)               | 2 (22.2%)                |         |
| Simple partial, complex partial, and GTC | 2 (8.7%)              | 2 (22.2%)                |         |
| Proposed/completed procedure |                         |                           | 0.308   |
| Left temporal lobectomy  | 10 (43.5%)              | 6 (66.7%)                |         |
| Another left resection    | 1 (4.3%)                | 0 (0%)                   |         |
| Right temporal lobectomy | 11 (47.8%)              | 2 (22.2%)                |         |
| Another right resection   | 1 (4.3%)                | 0 (0%)                   |         |
| Other                    | 0 (0%)                  | 1 (11.1%)                |         |
| Cause of epilepsy        |                         |                           | 0.694   |
| Cryptogenic (including mesial temporal sclerosis) | 16 (69.6%)              | 6 (66.7%)                |         |
| Traumatic brain injury    | 5 (21.7%)               | 1 (11.1%)                |         |
| Congenital brain abnormality | 2 (8.7%)              | 2 (22.2%)                |         |

Ordinal data was compared using the Wilcoxon rank-sum test. Categorical data was compared using Fischer’s test. P values < 0.05 considered significant.

Of antiepileptic drugs were not tracked, the number of agents and choice of drugs were comparable between the two groups. At the time of their decision to choose or defer surgery, all patients were on between 1 and 3 antiepileptic drugs. As seen in Table 2 there was no significant difference in the number of drugs that patients were on at the time of their decision; thus it is unlikely that cognitive side effect had a major impact on the patients’ choices. The most commonly administered agents were levetiracetam, lamotrigine, and carbamazepine. None of these are associated with severe cognitive slowing often seen with barbiturates or benzodiazepines. None of our patients were on either of those two classes of AED, indicating perhaps greater sensitivity in the surgical group to the adverse social effects of epilepsy.

The nonsurgical group reported that surgical fears were more influential factors in their decision. Specifically, patients in the nonsurgical group rated a general comfort (or discomfort) with surgery, fear of surgery in general, fear of complications during surgery, and concerns about complications due to comorbidities as significantly more important than did the surgical group. Often, patients elaborated their reasons here, expressing that the surgery was too risky to have without an absolute guarantee of seizure freedom. This is an important difference between groups because if a patient expresses intense fear of surgery, this could be addressed with multiple conversations with various providers, support groups, and other patients. Instead of suggesting surgery once, as is often the case, and assuming patients will understand that surgery offers the greatest chance of seizure freedom and make a decision based on our statistical logic, physicians might more gradually introduce the idea of surgery. Also, if a patient continuously expresses these surgical fears, the

4.2. Decision-Making Factors. Of our 36 factors, 12 differed significantly. Frequency and severity and length of time with seizures were more important factors in the decision for the surgical group. Furthermore, the surgical group cited the need/desire to be seizure-free, the stigma of epilepsy, embarrassment from seizures in public, and frustration with epilepsy as more important than the nonsurgical group,
Table 3: Importance of factors in epilepsy surgery decision making.

| Details of epilepsy                              | Surgical group (N = 23) | Nonsurgical group (N = 9) | P value |
|-------------------------------------------------|-------------------------|---------------------------|---------|
| Frequency and severity of seizures              | 3.48 (0.8)              | 1.89 (1.4)                | 0.002   |
| How long I have had seizures                    | 2.957 (1.4)             | 1.56 (1.7)                | 0.031   |
| Effects of epilepsy                              |                         |                           |         |
| Work limitations as a result of seizures        | 2.435 (1.7)             | 1.44 (1.4)                | 0.082   |
| The stigma of having epilepsy                   | 2.435 (1.8)             | 0.89 (1.8)                | 0.022   |
| Embarrassment from seizures in public           | 2.522 (1.6)             | 1.11 (1.7)                | 0.037   |
| Fear of death from seizures                     | 1.652 (1.5)             | 0.89 (1.4)                | 0.154   |
| Fear of physical injury from seizures           | 2.435 (1.6)             | 1.44 (1.2)                | 0.081   |
| Need/desire to be seizure-free                  | 3.783 (0.6)             | 2.0 (1.2)                 | 0.000   |
| Frustration with epilepsy                        | 3.522 (0.6)             | 1.33 (1.4)                | 0.000   |
| Disability benefits                             | 0.869 (1.4)             | 0.56 (1.0)                | 0.747   |
| Other people or group’s beliefs                  |                         |                           |         |
| Opinions of family members                      | 2.0 (1.6)               | 2.44 (1.7)                | 0.436   |
| Opinions of friends                             | 1.261 (1.4)             | 0.67 (1.0)                | 0.355   |
| My faith or religion                            | 1.565 (1.8)             | 0.78 (1.6)                | 0.236   |
| Surgical fears                                   |                         |                           |         |
| General comfort with surgery                     | 2.0 (1.5)               | 3.33 (0.9)                | 0.019   |
| Fear of surgery in general                      | 1.391 (1.4)             | 3.11 (1.2)                | 0.005   |
| Fear of being put under anesthesia               | 0.696 (1.3)             | 1.22 (1.5)                | 0.218   |
| Fear that I will not wake up after surgery       | 1.086 (1.5)             | 1.67 (1.7)                | 0.254   |
| Fear of complications during surgery            | 1.739 (1.5)             | 3.56 (0.5)                | 0.002   |
| Fear of memory (or other) cognitive problems after surgery | 2.478 (1.5) | 3.0 (1.7) | 0.172 |
| Concerns that my other health conditions may impact surgery | 0.652 (1.2) | 2.11 (2.0) | 0.045 |
| Hopes after surgery                              |                         |                           |         |
| Career opportunities                             | 2.13 (2.3)              | 1.56 (1.7)                | 0.399   |
| Future ability to drive                          | 2.652 (1.7)             | 1.78 (1.8)                | 0.143   |
| Doctor’s information about surgery               |                         |                           |         |
| The chances of success quoted to me by my doctor | 3.304 (1.1)             | 2.33 (1.4)                | 0.040   |
| The risk of complications during surgery quoted to me by my doctor | 2.13 (1.4) | 2.56 (1.5) | 0.413 |
| The risk of disability after surgery quoted to me by my doctor | 1.565 (1.4) | 2.22 (1.9) | 0.289 |
| Personal beliefs about the procedure             |                         |                           |         |
| My own understanding of the surgical procedure   | 2.565 (1.1)             | 2.78 (1.2)                | 0.602   |
| My belief that surgery would work                | 3.565 (0.7)             | 2.22 (1.2)                | 0.002   |
| Knowledge of others’ successes or failures with epilepsy surgery | 1.348 (1.6) | 1.78 (1.6) | 0.448 |
| The degree to which surgical treatment is proven scientifically | 2.739 (1.1) | 2.67 (1.3) | 0.982 |
| Medication effects                               |                         |                           |         |
| The number of medications I take (or took presurgery) | 2.869 (1.4) | 2.22 (1.3) | 0.150 |
| Physical side effects of seizure medications     | 2.174 (1.4)             | 1.78 (1.6)                | 0.467   |
| Cognitive or emotional side effects of seizure medication | 2.13 (1.6) | 1.56 (1.7) | 0.354 |
| Other treatment options                         |                         |                           |         |
| Alternative treatments that may be available to me in the near future | 0.522 (1.1) | 1.44 (1.8) | 0.184 |
| Availability of the vagal nerve stimulator      | 0.348 (0.9)             | 0.78 (1.2)                | 0.229   |
| The surgeon recommended the vagal nerve stimulator | 0.348 (0.8) | 0.44 (1.3) | 0.765 |
| The vagal nerve stimulator seemed safer          | 0.251 (0.8)             | 0.67 (1.3)                | 0.445   |

Values reported as mean (standard deviation). P value provided by the Wilcoxon rank-sum test.
Table 4: Patient sources of information and influences.

| Information Source                                                                 | Surgical group | Nonsurgical group | P value |
|-----------------------------------------------------------------------------------|----------------|-------------------|---------|
| My epilepsy doctor                                                                | 20 (87.0%)     | 8 (88.9%)         | 0.667   |
| My neurosurgeon                                                                  | 7 (30.4%)      | 1 (11.1%)         |         |
| A former patient who had surgery                                                  | 1 (4.3%)       | 0 (0%)            |         |
| Viewing the informational DVD, provided by the Penn Epilepsy Center               | 1 (4.3%)       | 0 (0%)            |         |
| My family and friends                                                             | 1 (4.3%)       | 0 (0%)            |         |
| The internet                                                                      | 5 (21.7%)      | 1 (11.1%)         |         |

Where did the patient gain the majority of their information regarding the surgical procedure? 0.667

| Influential Source                                                                 | Surgical group | Nonsurgical group | P value |
|-----------------------------------------------------------------------------------|----------------|-------------------|---------|
| My epilepsy doctor                                                                | 12 (52.2%)     | 3 (33.3%)         | 0.234   |
| My neurosurgeist                                                                  | 8 (34.8%)      | 0 (0%)            |         |
| A former patient who had surgery                                                  | 1 (4.3%)       | 0 (0%)            |         |
| My family and friends                                                             | 4 (17.4%)      | 3 (33.3%)         |         |
| Myself                                                                            | 3 (13.0%)      | 5 (55.6%)         |         |

Who is most influential in the patient’s decision? 0.234

Patients were allowed to choose multiple options; therefore, the column totals do not equal the total patients in each group. P value calculated with Fischer's exact test.

4.3. Patient Sources of Information and Influences. Questions regarding sources of information and influences on decisions showed a trend. The nonsurgical group was less likely to identify their doctor as most influential in their decision, and many more identified themselves as most influential. This could mean that there is an opportunity for epilepsy doctors to be more important in the decision-making process by increasing the number of conversations, following up more with patients, and otherwise building a strong rapport with patients so they will trust and follow medical recommendations. Such is of course conjecture; the nonsurgical patients may have a more intransigent style, and more exposure or dialogue may either have no benefit or may make them more entrenched in their beliefs which are discordant with those of their clinicians.

5. Conclusions

Access to medical care is a major issue in all branches of medicine and in epilepsy as well [9]. Typically researchers focus on lack availability of care or poor referral patterns [10]. We focused on patient attitudes as a barrier to care which we believe is a neglected variable. Our study reveals differences between patients who choose to have surgery and those who defer. These differences are social, personal, medical, and psychiatric and help create a profile of patients who are more likely opt against a procedure despite medical need and physician recommendation. Although our study had small statistical power due to the small sample sizes these findings may be helpful in generating further hypotheses on why patients decline recommended care, assisting in understanding the process of patient choice and, through open discussion, prevent unnecessary presurgical evaluations for patients who are adamantly against surgery regardless of medical opinion.

Appendix

A. Decision Making in Epilepsy Questionnaire

The following questionnaire is designed to assess why people chose to have epilepsy surgery or why they chose to defer such an operation. We thank you for your time and participation.
A.1. Demographic Information:

Patient number: ————
Place of Birth: ————
State of residence: ————
Level of education: ————
Marital Status: ————
Number of children (if any): ————
My ethnicity is best described as: ————

Did you require help to complete this form? (Circle your choice)
YES
NO

A.2. Questions about Your Seizures:

Please circle the best answer:

(1) My seizures are dangerous
TRUE
FALSE

(2) My seizures are disabling
TRUE
FALSE

(3) My seizures disrupt my life but are not severe
TRUE
FALSE

(4) My seizures bother me only slightly
TRUE
FALSE

(5) My seizures do not bother me at all
TRUE
FALSE

I have had seizures for how many years: ————
Age of onset of seizures: ————
Frequency of seizures: ————
(per week or per month or per year)

Are you currently employed: (circle your choice)
YES
NO

Are you currently on disability? (circle your choice)
YES
NO

Current medications: ————

Did you choose to have epilepsy surgery? (circle your choice)
YES
NO

Please rank how much each of the following influenced your decision about surgery. Please choose a response from 0 to 4 for each item. 0 means it was not important to you in your decision, and 4 means it was very important to you. If the factor does not relate to you, please choose N/A for Not Applicable. If you chose to have surgery, these questions are regarding these factors before surgery.

A.3. Factors in Choosing to Have or Not Have Surgery:

not important → most important

Frequency and severity of seizures:

N/A
0
1
2
3
4

Work limitations as a result of seizures:

N/A
0
1
2
3
4

How long I've had seizures:

N/A
0
1
2
3
4

The stigma of having epilepsy:

N/A
0
1
2
3
4
| Embarrassment from seizures in public: | Career opportunities: |
|--------------------------------------|----------------------|
| N/A                                  | N/A                  |
| 0                                    | 0                    |
| 1                                    | 1                    |
| 2                                    | 2                    |
| 3                                    | 3                    |
| 4                                    | 4                    |

| Fear of death from seizures:         | Disability benefits: |
|--------------------------------------|----------------------|
| N/A                                  | N/A                  |
| 0                                    | 0                    |
| 1                                    | 1                    |
| 2                                    | 2                    |
| 3                                    | 3                    |
| 4                                    | 4                    |

| Fear of physical injury from seizures: | My belief that surgery would work: |
|----------------------------------------|-----------------------------------|
| N/A                                    | N/A                               |
| 0                                      | 0                                 |
| 1                                      | 1                                 |
| 2                                      | 2                                 |
| 3                                      | 3                                 |
| 4                                      | 4                                 |

| Need/desire to be seizure-free:       | Opinions of family members: |
|---------------------------------------|-----------------------------|
| N/A                                   | N/A                         |
| 0                                     | 0                            |
| 1                                     | 1                            |
| 2                                     | 2                            |
| 3                                     | 3                            |
| 4                                     | 4                            |

| Frustration with epilepsy:            | Opinions of friends:         |
|---------------------------------------|-----------------------------|
| N/A                                   | N/A                         |
| 0                                     | 0                            |
| 1                                     | 1                            |
| 2                                     | 2                            |
| 3                                     | 3                            |
| 4                                     | 4                            |
| My faith or religion: | 2  
|---------------------|----|
| N/A                 | 3  |
| 0                   | 4  |

| Knowledge of other’s successes or failures with epilepsy surgery: | 2  
|---------------------------------------------------------------|----|
| N/A                                                           | 3  |
| 0                                                             | 4  |

| The chances of success quoted to me by my doctor: | 2  
|--------------------------------------------------|----|
| N/A                                              | 3  |
| 0                                                | 4  |

| The risk of complications during surgery quoted to me by my doctor: | 2  
|------------------------------------------------------------------|----|
| N/A                                                              | 3  |
| 0                                                                | 4  |

| The risk of disability after surgery quoted to me by my doctor: | 2  
|-----------------------------------------------------------------|----|
| N/A                                                             | 3  |
| 0                                                                | 4  |

| General comfort with surgery: | 2  
|------------------------------|----|
| N/A                          | 3  |
| 0                            | 4  |

My faith or religion:  
N/A
0
1
2
3
4

Knowledge of other’s successes or failures with epilepsy surgery:  
N/A
0
1
2
3
4

The chances of success quoted to me by my doctor:  
N/A
0
1
2
3
4

The risk of complications during surgery quoted to me by my doctor:  
N/A
0
1
2
3
4

The risk of disability after surgery quoted to me by my doctor:  
N/A
0
1
2
3
4

General comfort with surgery:  
N/A
0
1

Fear of surgery in general:  
N/A
0
1
2
3
4

Fear of being put under anesthesia:  
N/A
0
1
2
3
4

Fear that I won’t wake up after surgery:  
N/A
0
1
2
3
4

Fear of complications during surgery:  
N/A
0
1
2
3
4

Fear of memory (or other) cognitive problems after surgery:  
N/A
0
1
2
3
4
Concerns that my other health conditions may impact surgery:

N/A
0
1
2
3
4

Future ability to drive:

N/A
0
1
2
3
4

My own understanding of the surgical procedure:

N/A
0
1
2
3
4

The number of medications I take (or took pre-surgery):

N/A
0
1
2
3
4

Physical side effects of seizure medications:

N/A
0
1
2
3
4

Cognitive or emotional side effects of seizure medication:

N/A
0
1
2
3

Alternative treatments that may be available to me in the near future:

N/A
0
1
2
3
4

The degree to which surgical treatment is proven scientifically:

N/A
0
1
2
3
4

Availability of the vagal nerve stimulator:

N/A
0
1
2
3
4

The surgeon recommended the vagal nerve stimulator:

N/A
0
1
2
3
4

The vagal nerve stimulator seemed safer:

N/A
0
1
2
3
4

Other reasons: ——
A.4. Additional Questions Regarding Surgical Choice:

(1) Where did you gain most of your information regarding surgery:

(a) My epilepsy doctor  
(b) My neurosurgeon  
(c) Another member of the epilepsy center team  
(d) A former patient who chose to have surgery  
(e) Viewing the DVD (get name here?)  
(f) My family and friends  
(g) Other: ————

(2) Who was most influential in your decision to have, or not have, surgery?

(a) My epilepsy doctor  
(b) My neurosurgeon  
(c) Another member of the epilepsy center team  
(d) A former patient who chose to have surgery  
(e) Viewing the DVD (get name here?)  
(f) My family or friends  
(g) Other: ————

(3) How many different hospitals have discussed epilepsy surgery with you?

(Please circle one)  
1  
2  
3  
More than 3

(4) Do you feel that all of your questions regarding the proposed surgical procedure were answered?

YES  
NO

(5) Have you had surgery before?

YES  
NO

(6) Have you had a bad experience with surgery before?

YES  
NO  
If yes, please explain: ————

A.5. Items for Completion by Research Team:

Epilepsy Surgery

Procedure that was done: (to be filled in by MD)

—————

Procedure that was not done: (to be filled in by MD)

—————

Number of medication trials: ————

Etiology of epilepsy: ————

Types of seizures: ————

Comorbid depression: ————

YES  
NO

Other psychiatric disease: ————

YES  
NO

Does the doctor perceive the patient as mistrustful? ————

YES  
NO

Is the patient well-adherent with medical plans? ————

YES  
NO

Neuropsychological testing results: ————

IQ: ————

Does the patient use illegal drugs: ————

Does the patient smoke: ————

Does the patient drink alcohol excessively: ————

Wada results: ————

MRI results: ————

PET results: ————

References

[1] P. Kwan and M. R. Sperling, “Refractory seizures: try additional antiepileptic drugs (after two have failed) or go directly to early surgery evaluation?” Epilepsia, vol. 50, no. 8, pp. 57–62, 2009.

[2] S. Wiebe, W. T. Blume, J. P. Girvin, and M. Eliaziw, “A randomized, controlled trial of surgery for temporal-lobe epilepsy,” The New England Journal of Medicine, vol. 345, no. 5, pp. 311–318, 2001.

[3] J. Engel Jr., S. Wiebe, J. French et al., “Practice parameter: temporal lobe and localized neocortical resections for epilepsy,” Epilepsia, vol. 44, no. 6, pp. 741–751, 2003.

[4] J. F. Téllez-Zenteno, R. Dhar, and S. Wiebe, “Long-term seizure outcomes following epilepsy surgery: a systematic review and meta-analysis,” Brain, vol. 128, no. 5, pp. 1188–1198, 2005.

[5] K. Swarztrauber, “Barriers to the management of patients with surgically remediable intractable epilepsy,” CNS Spectrums, vol. 9, no. 2, pp. 146–152, 2004.
[6] K. Swarztrauber, S. Dewar, and J. Engel Jr., “Patient attitudes about treatments for intractable epilepsy,” *Epilepsy and Behavior*, vol. 4, no. 1, pp. 19–25, 2003.

[7] C. T. Anderson, K. Davis, and G. Baltuch, “An update on brain stimulation for epilepsy,” *Current Neurology and Neuroscience Reports*, vol. 9, no. 4, pp. 327–332, 2009.

[8] C. Carlson, P. Dugan, and J. French, “Progression to epilepsy surgery following presurgical evaluation,” *Epilepsy Currents*, vol. 12, no. 1, p. 125, 2012.

[9] R. Kobau, Y. Luo, M. Zack, S. Helmers, and D. J. Thurman, “Epilepsy in adults and access to care—United States, 2010,” *Morbidity and Mortality Weekly Report*, vol. 61, no. 45, pp. 909–913, 2012.

[10] Z. Haneef, J. Stern, S. Dewar, and J. Engel, “Referral pattern for epilepsy surgery after evidence-based recommendations: a retrospective study,” *Neurology*, vol. 75, no. 8, pp. 699–704, 2010.
