Epilepsy & Behavior 28 (2013) 52–65

Contents lists available at SciVerse ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh

Patient perceptions and barriers to epilepsy surgery: Evaluation in a large health region

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ARTICLE INFO

Article history:
Received 6 March 2013
Accepted 12 March 2013
Available online 7 May 2013

Keywords:
Questionnaire
Survey
Patient expectations
Knowledge
Surgical risk
Epilepsy surgery
Drug-resistant epilepsy
Barriers
Canada

ABSTRACT

Purpose: Despite evidence that carefully selected patients with refractory focal epilepsy benefit from epilepsy surgery, significant delays remain. We examined patient knowledge and perceptions regarding epilepsy surgery.
Methods: A 5-minute questionnaire was administered to consecutive adults with focal epilepsy seen in the epilepsy clinic in a large Canadian health region. Survey items assessed the following: (1) knowledge of surgical options, (2) perceptions about the risks of surgery vs. ongoing seizures, (3) disease disability, (4) treatment goals, and (5) demographic and socioeconomic variables. Patient responses were compiled to calculate a "Barriers to Epilepsy Surgery Composite" (BESC) score.
Results: Of 129 eligible patients, 107 completed the questionnaire (response rate: 83%). The average BESC score was 60/100. Apprehension about epilepsy surgery was less likely among patients who had previously undergone epilepsy surgery and those born in Canada.
Discussion: People with epilepsy often have hindering perceptions that can contribute to delays in surgical care.

1. Introduction

Seizures in approximately one-third of patients with epilepsy are medically intractable [1,2]. Years of drug-resistant epilepsy carry longstanding consequences, including poor quality of life (QOL) [3,4], cognitive decline [5], premature mortality [6], and high societal costs [7,8].

Two randomized controlled trials provide class I evidence supporting a role for surgery in temporal lobe epilepsy [9,10], the latter emphasizing the benefit of early intervention. American Academy of Neurology clinical practice guidelines dating back a decade state that epilepsy surgery should be considered in patients with drug-resistant focal epilepsy [11]; yet delays between epilepsy diagnosis and surgical evaluation are significant and consistent across reports, averaging 20 years in adults and 10 years in children [12–14]. Despite harboring pioneers in the field amidst a strong universal health-care system, Canada provides no exception [15].

Multiple factors contribute to these delays, including a lack of adequate resources as well as varying physician knowledge, attitudes, and referral practices. Patient factors also play a critical role, including patient disability and poor self-management skills, limited education with frequent misinformation, and minority concerns surrounding racial [16–19], socioeconomic [20], and ethnic/cultural issues [14,19]. Additionally, patients tend to have exaggerated perceptions of epilepsy surgical risks, and such attitudes can be highly influential in surgical decision making [19,21].

We aimed to identify patient barriers to accessing epilepsy surgical evaluations as well as to assess patient expectations of epilepsy surgery in a Canadian health region. We hypothesized that patients with focal epilepsy would (1) demonstrate a lack of knowledge about surgical options, (2) overestimate the risks of epilepsy surgery, and (3) underestimate the risks of ongoing poorly controlled seizures.

2. Methods

2.1. Questionnaire development

A literature review was conducted prior to the initial drafting of the questionnaire to aid with establishing content validity. Important

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http://dx.doi.org/10.1016/j.yebeh.2013.03.013

questions and topics from the literature were either modified or directly included as items in our questionnaire [9,11,17–19,22–27] (see Appendix A). The 33-item questionnaire was drafted by a team composed of epileptologists, an epilepsy fellow, and research assistants. Survey items assessed patients' (1) knowledge of surgical options, (2) perceptions about the risks of surgery vs. ongoing seizures, (3) disease disability, (4) treatment goals, and (5) demographic and socioeconomic variables.

The initial questionnaire was piloted in a sample of ten patients with epilepsy in order to assess face validity and clarity. The time needed to complete the questionnaire was noted for each participant, and all pilot study participants provided written and verbal feedback. The questionnaire was then modified based on the results of the pilot study and further discussion. The final questionnaire (see Appendix A) was determined to have a Flesh–Kincaid grade level of 10.1 and a Flesch Reading Ease score of 48.7. Although this represents a higher reading level than ideal, this was a result of the medical nature of the questionnaire. When the terms “epilepsy,” “seizure(s),” “seizure disorder,” and “surgery” were removed, the reading difficulty was decreased to a Flesh–Kincaid grade level of 7.4 and a Flesch Reading Ease score of 64.6, which is an acceptable reading level for this population. These terms were not eliminated as they are crucial to the content of the questionnaire and are familiar to our patient population.

2.2. Patient recruitment

We aimed to recruit one hundred consecutive adult patients with focal epilepsy from an outpatient epilepsy clinic at a large tertiary carecenter. Patients were excluded if they had a generalized or undetermined epilepsy syndrome (unclear if they had epilepsy or not), end-stage progressive or neurodegenerative disease, or a severe psychiatric comorbidity (e.g., severe psychosis or suicidal ideation) precluding ability to participate. Patients with cognitive impairment were included if a proxy was available to complete the survey on their behalf. The treating physician or a research assistant prescreened clinic lists to identify potentially eligible patients. Patients completed and returned the consent form and questionnaire in the clinic's waiting room. Questionnaires were de-identified to ensure patient confidentiality.

2.3. Ethics approval

Written informed consent was obtained from all patients participating in the study. This study was approved by the Conjoint Health Research Ethics Board at the University of Calgary.

2.4. Statistical analysis

Descriptive statistics examined questionnaire responses and characterized the population. Missing data were handled using regression-based multiple imputation. To assess how different patient characteristics relate to attitudes towards surgery, the responses to each of the eight questions representing “patient-perceived barriers to epilepsy surgery” were linearly transformed to create a composite score ranging from 17.5 to 100 (higher score = greater barriers). The questions are summarized in Table 1.

A sample of 107 patients provided 89% power, with a two-tailed alpha at 0.05, to detect a small effect size ($f^2 = 0.1$) in a linear regression model testing eight predictor variables. Linear regression was used to examine the relationship between the “Barriers to Epilepsy Surgery Composite” (BESC) score and the following variables: epilepsy severity, education, whether the patient was born in Canada, and whether the patient had previously had epilepsy surgery. These variables were selected based on our original hypotheses and their clinical importance. All analyses were performed using SPSS 19.0 or STATA 10.0.

3. Results

3.1. Participant characteristics

In total, 107 out of 129 eligible consecutive patients with focal epilepsy completed the questionnaire during the survey period (March 12th–April 20th, 2012), giving a response rate of 83%. Only 4 patients (3.7%) had the survey completed by a proxy. The mean age of participants was 42.0 years, and 53.3% of participants were female. The majority of patients reported having at least some postsecondary education; employment was the most common source of income (Table 2). Most participants were identified as White and were native to Canada (Table 2). Just over half of the patients reported a household income of under $50,000, with a median income of $41,000–50,000. A minority (16.8%) of patients were receiving some form of social assistance, with 9.7% receiving disability coverage.

The average epilepsy duration was 19.8 years, and 40.2% of participants were currently seizure-free. Approximately one-fifth of the population had already undergone epilepsy surgery (Table 2), with an average time from epilepsy onset to first surgery of 11.2 years and a mean age at surgery of 24 years (SD: 11.5). The majority of participants reported having tried at least three antiepileptic drugs (AEDs) and that they were having side effects from their current AED(s) (Table 2). Eighty-seven percent of patients considered their epilepsy/seizure disorder to be disabling.

Among the indicators of epilepsy severity (such as seizure frequency, number of AEDs tried, presence of side effects, and whether seizures

Table 1
Contribution of individual questions to the “patient-perceived barriers to epilepsy surgery” model.

Question	Standardized β	p
In general, brain surgery for epilepsy/seizure disorders is more dangerous than having seizures that are not controlled.	.253	<0.001
Would you have brain surgery if you could be guaranteed that you would never have another seizure and that there would be no damage to your brain, even if this meant staying on some anti-seizure medication?	.252	<0.001
If you were considering having brain surgery for your epilepsy/seizure disorder, what would you be worried about?	.252	<0.001
I would rather try (or have already tried) alternative medicine options (e.g., *herbs*, *vitamins*) before having brain surgery for my epilepsy/seizure disorder.	.243	<0.001
In your opinion, how dangerous is brain surgery for carefully chosen people with epilepsy/seizure disorders?	.240	<0.001
Do you think that brain surgery for epilepsy/a seizure disorder should only be considered *a last resort* (i.e., when you have already tried all other medications and treatments)?	.222	<0.001
In your opinion, what is the risk of serious side effects (e.g., paralysis, problems seeing) from brain surgery for epilepsy/seizure disorders?	.197	<0.001
I would rather take part (or have taken part) in a research (experimental) study testing a new non-surgical seizure treatment before having brain surgery for epilepsy/ seizure disorder.	.194	<0.001

Questions were standardized to account for differences in response options. A larger standardized β indicates a larger contribution to the overall composite score.