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Review

Perceptions of epilepsy surgery: A systematic review and an explanatory model of decision-making

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ABSTRACT

Background: Clear evidence supports the benefits of surgery over medical therapy for patients with refractory focal epilepsy. Surgical procedures meet the needs of fewer than 2% of those eligible. Referral to a tertiary epilepsy center early in the course of disease is recommended; however, patients live with disabling and life-threatening seizures for an average of 22 years before considering surgical treatment. Reasons for this treatment gap are unclear.
Purpose: A critical analysis of the literature addressing perceptions of surgical treatment for epilepsy is placed in the context of a brief history and current treatment guidelines. Common conceptual themes shaping perceptions of epilepsy surgery are identified.
Data sources: Data sources used for this study were PubMed–MEDLINE and PsycINFO from 2003 to December 2013; hand searches of reference lists.
Data synthesis: Nine papers that addressed patient perceptions of surgery for epilepsy and three papers addressing physician attitudes were reviewed. Treatment misperceptions held by both patients and physicians lead to undertreatment and serious health consequences. Fear of surgery, ignorance of treatment options, and tolerance of symptoms emerge as a triad of responses central to weighing treatment risks and benefits and, ultimately, to influencing treatment decision-making. Our novel explanatory framework serves to illustrate and explain relationships among contributory factors.
Limitation: Comparisons across studies are limited by the heterogeneity of study populations and by the fact that no instrument has been developed to consistently measure disability in refractory focal epilepsy.
Conclusion: Exploring the components of decision-making for the management of refractory focal epilepsy from the patient's perspective presents a new angle on a serious contemporary challenge in epilepsy care and may lead to explanation as to why there is reluctance to embrace a safe and effective treatment.

1. Introduction

Epilepsy is identified globally as a leading neurological disorder for years of life lost to disease [1]. One-third of patients with this complex disease suffer from seizures that are chronic and medically refractory [2]. Although antiseizure drugs form the mainstay of treatment, drug side effects are often perceived as worse than the seizures themselves [3]. The impact of refractory epilepsy is well described and extends beyond the experience of paroxysmal seizures. Aspects of life, work, and play across all stages of the lifespan maybe negatively affected [4]. The negative contribution of comorbid conditions in the management of uncontrolled epilepsy including diminished memory and cognition [5], poor general health [6], injuries [7], and high risk of sudden unexpected death (SUDEP) [8] cannot be underestimated. Not unexpectedly, around 25% of patients with uncontrolled epilepsy experience anxiety, hopelessness, and suicidal thoughts [9].

Unfortunately, stigma and social discrimination frequently influence therapeutic decision-making, resulting in undertreatment and ultimately compounding disability [7,10]. Nowhere is this more evident than in the reluctance to consider the benefits of resective brain surgery for refractory epilepsy. In carefully selected patients, the benefits and safety of surgery are well established [11,12] and not only include freedom from seizures but also improved long-term survival rates and better quality of life [13,14]. Unfortunately, and for unclear reasons, much hesitation appears to surround this option. Those who do receive surgery often do so after tolerating their disease for an average of 22 years [15,16].

Thus, the goal of this review is to analyze the literature addressing perceptions of epilepsy surgery from the perspectives of both clinicians

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and patients in order to determine the factors likely to either motivate for or drive underutilization of surgery. Our review is placed within a historical context to highlight both the timeliness of this discussion and the clinical implications of this important debate. In a preliminary explanation, we assert that a complex process of treatment decision-making lies at the center of this debate and influences physician and patient behaviors alike. We include a case study of one person's disease experience to illustrate the challenging nuances of decision-making faced by a patient with refractory focal epilepsy.

2. Historical background

The Palm Desert Conferences held in 1986 and 1992 brought together interdisciplinary experts in epilepsy from around the world. This collaboration emphasized the role of surgery in seizure control and reversal of disability in appropriately selected candidates. Encouragingly, this led to a doubling of the worldwide number of epilepsy centers [17,18].

In 1993, an estimated 2000 surgeries per year were performed in the US, representing 1.5–2% of eligible patients [19]. At this time, the duration from onset of disease to referral was more than 20 years [16], creating the potential for irreversible psychosocial disability and necessitating a shift in clinical focus to find ways to reduce these unacceptable delays. Two randomized controlled trials (RCT) resulted. Both trials were for temporal lobe epilepsy (TLE) which is the most common, most refractory, and most surgically remediable form of epilepsy [18].

The first of these studies published in 2001 supported the benefits of surgery over continued medicine trials [20]. In this study, duration of illness varied widely and included those with long-standing disease. Nevertheless, 64% of the patients were seizure-free for one year after surgery. The goals of the second study were to improve access to treatment early in the course of disease and to address the myth that surgery is an experimental, last resort. Surgically, eligible patients were identified based on rigorous and complex inclusion criteria including duration of refractory seizures of no more than two years. Subjects were randomized to either a surgical arm or a medical arm, and results of the treatment groups were compared 24 months later. In this study, 85% of those randomized to the surgical arm were seizure-free for 24 months and showed significant improvements in quality-of-life measures. At 24 months of follow up no subjects randomized to the medical arm were seizure-free [21]. In preparation for this landmark study, focus groups were conducted to determine how patients view treatment for epilepsy and whether they would participate in a surgical study of the type proposed. This was the first time that subjective perceptions of treatment options and barriers to surgery were sought from patients in their own words [22].

Practice guidelines of the American Academy of Neurology (AAN) published in 2003 recommend that patients be referred to an epilepsy center when first-line drugs are found to be ineffective for seizure control [11]. Unfortunately and for unclear reasons, neither the AAN guidelines nor the Class I evidence supporting surgical benefits has impacted optimal referral practices [23–26], leaving referral rates to comprehensive epilepsy centers unchanged in over two decades. Furthermore, patients continue to be referred late in the course of disease [26,27]. As a consequence, current standards of practice in epilepsy care are seriously questioned by epilepsy specialists [15].

3. Methods

Acceptance of epilepsy surgery (ES) is dependent on the knowledge and attitude of general neurologists offering primary treatment to patients and the perceptions, experience, and expectations of patients agreeing to treatment. We undertook a systematic search of the databases PubMed–MEDLINE and PsycINFO for articles published between 2003 and 2013 and explored these two viewpoints. This reflects the decade immediately after the first RCT [20] and the publication of the AAN practice guidelines [11]. Search terms related to patient and provider perceptions of surgery for epilepsy were considered including "barriers", "surgical expectations", "attitudes towards illness", and "expected outcomes" of ES. A small body of work was identified, and all papers ($N = 12$) were included. Our analysis was focused on how key concepts were evaluated in the published series.

4. Results

The nine studies addressing patient perceptions are summarized in Table 1 to provide a concise overview of a small number of descriptive studies in chronological order and to highlight potential changes in key concepts over time. The important contribution of physician perspective was investigated in only three studies [28–30]. Together, the twelve studies reveal opinions of surgery and common reasons why surgery might or might not be embraced. Further analysis allowed for the extrapolation of major properties and overarching themes and supports the development of our explanatory diagram.

Study methods shown in Table 1 utilize mostly surveys or focus groups. Comparing studies was difficult because of heterogeneity in study samples, including the following: a) patients with both controlled and uncontrolled seizures [31], b) patients with uncontrolled epilepsy but not necessarily surgical candidates [22,32–34], and c) patients who are culturally diverse and with to have economic disadvantages [35]. Only two papers [36,37] address the subjective perspectives of surgically identified patients. The first of these includes a cohort of patients screened and eligible for surgery ($n = 33$) and compares reasons for accepting or refusing surgery [36]. The second [37] centers on the informational needs of postsurgical patients, focusing on content and optimal ways of delivering information about surgery, but neglects the concurrent contribution of the physician viewpoint [37].

Treatment perceptions and acceptance of ES are determined in part by the knowledge and attitude of the physician guiding treatment. However, whether patients act on physician recommendations rests on many patient-related contributory factors. We identified the factors influencing both viewpoints, with an emphasis on the patient's perception.

4.1. Factors influencing physician perceptions

Physician attitudes and treatment-related behaviors are influenced by both professional experience and personal beliefs [38]. Physician misinformation about inclusion and exclusion criteria for surgery, inadequate understanding of the concept of drug resistance [29,30], unfamiliarity with surgical procedures for epilepsy, and underappreciation of positive surgical outcomes [28] leave many patients to arrive at tertiary epilepsy centers by chance [37]. Although the reasons for physician reluctance to refer to tertiary centers are unclear [27], physician uncertainty about surgery for epilepsy presents a powerful barrier to patient acceptability and ultimately results in reduced access to optimal care [22,28,29,37]. Furthermore, advancing age should not discourage referral [12]. Comprehensive evaluation for older patients is an important consideration since drug therapy in this age group presents many challenges, including risks of adverse drug interactions, cognitive side effects, dizziness, imbalance, and falls [39]. Although published series are few, surgery is safe and effective in patients over sixty [40], and outcomes are comparable with those of younger patients [41].

4.2. Factors influencing patient perceptions

From the literature, the factors shaping patient perceptions can be collectively organized around four cardinal points, namely, personal views about disease severity, treatment experiences, expectations about treatment, and associated cognitive aspects. These four points diagrammed in Fig. 1 are interspersed by demographic factors