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# Changing the neurology policy landscape in the United States: Misconceptions and facts about epilepsy

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## ABSTRACT

Epilepsy has a relatively high prevalence, and diagnosis and treatment are often challenging. Seizure freedom without significant side effects is the ultimate goal for both physicians and patients, but not always achievable. In those cases, the treatment goals of patients and providers may differ. In the United States, many clinicians continue to prescribe older AEDs, even though newer AEDs have a more desirable safety and tolerability profile, fewer drug–drug interactions, and are associated with lower epilepsy-related hospital visits. Newer AEDs are more commonly prescribed by neurologists and epilepsy center physicians, highlighting the importance of access to specialty care. We report that antiepileptic drugs are not the dominant cost driver for patients with epilepsy and costs are considerably higher in patients with uncontrolled epilepsy. Poor drug adherence is considered a main cause of unsuccessful epilepsy treatment and is associated with increases in inpatient and emergency department admissions and related costs. Interventions and educational programs are needed to address the reasons for nonadherence. Coverage policies placing a higher cost burden on patients with epilepsy lead to lower treatment adherence, which can result in higher future health care spending. Epilepsy is lagging behind other neurological conditions in terms of funding and treatment innovation. Increased investment in epilepsy research may be particularly beneficial given current funding levels and the high prevalence of epilepsy.

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## 1. Introduction

Epilepsy is a complex neurological disorder characterized by the occurrence of abnormally excessive or synchronous neuronal discharges, a predisposition to generate seizures, and characteristic cognitive, psychological, and social consequences [1]. Seizure types and their severity vary widely in epilepsy and can occur with unpredictable frequency [2,3]. The recent literature has dedicated much attention to the significant health and financial burden associated with epilepsy [4–6]. Unfortunately, much of the existing thinking surrounding epilepsy stems from a time when epilepsy was less well understood. We clarify a number of common misconceptions regarding epilepsy and discuss the more nuanced reality of today.

## 2. Epilepsy is relatively common in all age groups, has a multifaceted presentation, and can impact quality of life

Many people do not think of epilepsy as common. Based on patients who had been diagnosed with epilepsy between 1960 and 1979, previous estimates suggest that one in 26 people will develop epilepsy during their lifetime [7,8]. Our understanding of epilepsy has since improved, and this estimate may require revision. In fact, epilepsy is relatively common, with an incidence of approximately 50 new cases/100,000 persons/year and a prevalence of around seven cases/1000 people, representing approximately 4.1 million (1.8%) U.S. adults [9–11]. A recent retrospective, observational U.S. claims database analysis reported an epilepsy incidence of 79.1/100,000 people and a prevalence of 8.4 cases/1000 people [12].

Epilepsy can appear at any age, but incidence rates show a bimodal distribution with higher incidences occurring in early childhood and in the elderly [13]. Epilepsy incidence in children ranges from 41 to 187/100,000, with higher incidences in underdeveloped countries [14]. Epilepsy prevalence in children ranges from 3.2–5.5/1000 in developed countries and 3.6–44/1000 in underde-

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veloped countries [14]. Epilepsy incidence in the elderly is now higher than in children and the prevalence is expected to increase [15].

Most people associate epilepsy with tonic-clonic seizures, but epilepsy has a multifaceted presentation with a range of severities, seizure types, and etiologies [2]. Focal seizures are the predominant seizure type and occur more frequently than generalized seizures [16]. Epilepsy can appear without obvious cause or as a consequence of stroke, tumors, infections, or traumatic brain injury [17,18]. The most common causes of epilepsy in younger patients include congenital, developmental, and genetic disorders; cerebrovascular disease is a common cause in elderly patients [18]. In developing countries (particularly in the tropics), sequelae associated with parasitic and viral infections are a common etiology for epilepsy in children [19].

Living with epilepsy involves more than just seizures: patients face numerous challenges, including comorbid diagnoses and an increased risk of sudden death [2]. Sudden death in epilepsy (SUDEP) is the most common cause of epilepsy-related death with at least 2750 U.S. cases/year [20]. Recent estimates suggest that SUDEP affects approximately 1/4500 children and 1/1000 adults [21]. Up to 84% of patients with epilepsy have at least one comorbid condition [22]. Patients with epilepsy also face social challenges in independent living and in school, driving limitations, and employment uncertainties [2,23]. Moreover, epilepsy remains highly stigmatized, which negatively affects quality of life (QoL), leads to anxiety and depression, and can result in poor treatment adherence [2,24].

### 3. Epilepsy is difficult to diagnose, which may lead to treatment delays

Another common misconception is that epilepsy is straightforward to diagnose. Diagnosing epilepsy can be challenging and may lead to considerable delays from initial presentation to diagnosis and treatment [25]. Seizures occurring during this delay period can be detrimental to brain health and function [26].

The initial presentation is the first step in the diagnostic process, but a substantial proportion of patients delay seeking medical assessment for seizures [27]. Patients with nonconvulsive seizures or those with socioeconomic disadvantages are more likely to delay medical consultation [27]. Reasons for such delays include being underinsured or lacking health care insurance, difficulties in obtaining timely neurologist appointments, concerns about driving limitations, and stigma [28]. Treatment delays also may be because of geographic reasons—some patients may have limited or no access to neurologists or epileptologists.

Part of the reported delay in epilepsy diagnosis may be because of the previous International League Against Epilepsy (ILAE) guidelines in which a patient was required to have two unprovoked seizures for an epilepsy diagnosis and its subsequent treatment. The revised guidelines now require just one unprovoked seizure with a 60% chance of a second seizure for an epilepsy diagnosis [29]. In conjunction with the ILAE, the American Academy of Neurology published guidelines on managing adult patients with a first unprovoked seizure. Although immediate therapy with antiepileptic drugs (AEDs) likely reduces recurrence risk, such treatment does not always improve patients' QoL [30].

Another challenge in diagnosing epilepsy is that several other disorders can be confused with epilepsy. Approximately 25% of patients diagnosed with epilepsy may initially be misdiagnosed; psychogenic attacks or syncope are most commonly mistaken for epilepsy [31].

### 4. Epilepsy treatment is challenging and needs to be tailored to individual patients

Accurately diagnosing epilepsy and the specific seizure type is important in determining effective treatment, but identifying which patients will benefit from a specific therapeutic approach can be challenging [32]. Not all AEDs effectively treat all seizure types—although one AED may be effective in treating some seizure types, the same AED may aggravate others, which is especially relevant for patients with mixed seizure disorders [33,34]. Carbamazepine, for example, is effective in treating focal and generalized tonic-clonic seizures, but can exacerbate myoclonic and absence seizures [34,35].

Individualized treatment is needed because efficacy and tolerability vary according to patients' age and comorbidities, and may differ between patients with the same epilepsy syndrome [15,36,37]. Elderly patients have more comorbidities, including cardiovascular disease and psychiatric disorders, and are more likely to take concomitant medications, increasing the potential for drug–drug interactions, particularly with enzyme-inducing AEDs [15,38–40]. AED selection is further complicated by the presence of age-related metabolic changes that reduce drug clearance and increase pharmacodynamic sensitivity, making elderly patients more susceptible to adverse events [15,39].

Another challenge in treating epilepsy is finding the right balance between optimal AED dosing for seizure control and tolerability. The mantra for treatment has often been to 'start low, go slow'. Slow AED titration with low starting doses often minimizes adverse events. However, slow titration can be harmful to patients with high seizure frequency, as additional seizures can negatively impact global cognitive abilities and QoL [41,42]. AED titration may also result in greater anxiety for patients [43], and has been associated with higher health care resource use and costs compared with maintenance treatment [44]. Due to the mantra 'titrate to effect', patients with new-onset seizures or infrequent seizures are often titrated to the lowest possible dose, which may leave them vulnerable to more seizures. The suggested strategy is to titrate the AED to a target dose that has proven effective in clinical trials and subsequent clinical practice, and to then make dose adjustments in the event of side effects of recurrent seizures [45]. For patients with an immediate need for seizure control, it may be beneficial to reach effective doses faster, which can be achieved using AEDs that are initiated at higher doses or have shorter titration schedules [46,47]. Determining which patients will respond best to different titration approaches can be difficult to achieve in clinical practice and can leave patients receiving ineffective AED dosages for extended periods of time [47]. Dosage optimization requires skill and patience and can lead to prematurely switching patients to alternative therapies without exploring full dosage ranges [47]. Additionally, the routine capture of seizure frequency that is easily retrievable from electronic medical records has not been implemented, which further exacerbates problems measuring efficacy tailored to individuals and fails to support a key measure of the quality of care [48].

Although many patients eventually achieve seizure freedom, approximately one-third remain AED treatment-resistant [49,50]. Failure to control seizures with the first AED treatment is predictive of subsequent AED treatment failures, although small numbers of patients will benefit from each new AED, with some becoming seizure-free [50–52]. Drug-resistant epilepsy is associated with increased morbidity and mortality, and better treatment options for these patients are clearly needed [53]. Drug-resistant epilepsy must be defined early, and epilepsy surgery or other alternative treatments must be considered as soon as possible [53]. Epilepsy surgery should be considered for any patients with drug-resistant focal epilepsy, although not all patients will be appropriate candidates

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