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Driving with drug-resistant and controlled seizures from a patient's perspective: Assessment of attitudes and practices

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ABSTRACT

Background: Driving restrictions in epilepsy are intended to safeguard public and personal safety; however, these limitations inhibit socialization, restrict employment, and reduce self-esteem in patients with seizures. A large proportion of patients with seizures continue to drive, and factors leading to noncompliance with driving regulations are poorly understood. Thus, the patients' perspective on driving safety is not incorporated into the existing counseling tools on driving safety in epilepsy. The present study assessed social, economic, and psychological perceptions related to driving restrictions in patients with refractory and pharmacotherapy-controlled seizures at the single epilepsy center and identified impediments for safe driving.

Methods: Data were obtained from an anonymous survey completed by 25 adult patients in the presurgical group (PG) with refractory epilepsy and 46 patients in the ambulatory group (AG) with confirmed epilepsy which did not meet criteria for refractoriness. The questionnaire (administered via Research Electronic Data Capture (REDCap)) addressed seizure and driving history, knowledge of driving restrictions, and social consequences of losing driving privileges.

Results: Eighty-seven percent of all responders experienced seizures with alteration of awareness; however, 34% of patients continued to drive during the time when they were legally restricted, and 6% had accidents related to seizures. All responders reported their seizure status accurately to the treating physician, and 93% understood state-based driving restrictions. The median time from the last seizure was shorter, and the duration of last driving restriction was longer in the PG compared with the AG (1 vs. 20 weeks, and 12 vs. 24 weeks, respectively). Despite that, the proportions of patients driving at the time of survey were not significantly different between the two groups. Nearly 80% of all patients stated that driving restrictions reduced their quality of life, and 70% believed that these restrictions carry a social stigma. Employment was chosen to be the most affected by driving restrictions from a list of four social domains by the majority of patients in both groups. Notably, the employment rate was 26% higher in the AG compared with the PG. The lack of public transportation was regarded as a hurdle by more than 60% of patients in each group with greater than two-thirds of patients relying on other drivers for transportation.

Conclusions: These findings suggest that patients with refractory and pharmacotherapy-controlled seizures are similarly likely to drive a vehicle, disregarding a practitioner's advice and state restrictions. The lack of public transportation is a shared constraint and likely leads to reduced compliance with driving regulations. Driving restrictions carry social stigma and limit the employment of patients with epilepsy, regardless of the refractory seizure status.

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1. Introduction

Freedom to drive is an ultimate determinant of social independence and quality of life in patients with epilepsy [1,2]. In modern society, driving privileges constitute economic necessity while driving restrictions limit autonomy, restrict access to employment, and reduce

self-esteem [1]. While the awareness of risks associated with driving and ongoing seizures was established more than a century ago, the concept of a seizure-free interval has not been applied to driving until the 1950s [3]. Consequently, in 1970, the consensus in the United States and Great Britain was reached that people with epilepsy should be permitted to drive if their seizures are adequately controlled [3,4]. This concept was further refined by specific state regulations governing the public safety and personal protection of drivers whose seizures are well-controlled.

The perception of adequate seizure control, which is largely based on the frequency of seizures and the duration of the seizure-free interval,

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has been at the heart of all state-mandated driving regulations [3,5]. Despite that, there is no evidence-based justification for the duration of seizure-free intervals chosen by individual states [6]. Moreover, the efforts to shorten the duration of the restriction period or imposition of mandatory reporting on the part of treating physicians by certain states do not appear to increase the number of seizure-related crashes [7,8]. While some patients with uncontrolled seizures remain behind the wheel due to the lack of familiarity with the relevant state driving restrictions, many have been properly counseled but continue to drive either out of necessity or for retreat [9]. The factors contributing to disobedience in patients who are cognizant of associated medical and legal risks are not well-understood. Furthermore, it is not clear whether the diagnosis of refractory epilepsy affects a patient's attitude toward safe driving. Patients with drug-resistant epilepsy have been shown to have less mature social adjustment, greater impulsivity, higher levels of neurocognitive and psychiatric comorbidities, and greater effects of polypharmacy compared with patients with well-controlled seizures [10]; these factors could contribute to different attitudes toward driving restrictions and promote distinct patterns of disobedience. The present study compares the driving responses in patients with refractory and pharmacologically-controlled seizures treated at the single epilepsy center.

Personalized medical care and targeted counseling may allow patients with certain seizures to drive and improve their quality of life [1]; however, the tools for effective counseling of these patients are currently lacking. With the predominant focus of literature being on the perspective of medical professionals [8,11], patients' perceptions and subjective experiences are rarely incorporated into the existing tools [12,13]. In the present cross-sectional study, we examined differences in clinical, demographic, and social factors leading to noncompliance with driving restrictions between patients with refractory seizures referred for epilepsy surgery and those treated pharmacologically by assessing the barriers for safe driving. This research will allow us to clarify the areas where counseling requires further emphasis and will help to identify the resources necessary to support abstinence from driving.

2. Materials and methods

2.1. Selection of participants

This research was based on a cross-sectional design. Data were obtained from an anonymous survey completed by all consenting adult patients with medically refractory epilepsy in the presurgical group (PG) and patients with pharmacologically-controlled seizures in the ambulatory group (AG). The participants for the survey were identified and recruited using the following inclusion criteria: age 19 years and above, current or previous possession of driving license, and diagnosis of epilepsy established based on the clinical history and electroencephalography (EEG) findings. Patients with cognitive impairment, nonepileptic spells, and patients who had never driven a vehicle were excluded. The participants from the AG were recruited during their initial consultation or return visits to the ambulatory epilepsy clinic. Seizures were considered to be pharmacologically-controlled if they did not recur within the time equal to or greater than three inter-seizure intervals within the previous 2 years [14]. The participants from PG were recruited while they were admitted to the epilepsy monitoring unit (EMU) during presurgical evaluation for epilepsy surgery. The diagnosis of refractory epilepsy and selection of candidates for presurgical evaluation were based on the established criteria [15]. Participants were recruited by three epilepsy practitioners including one board-certified epileptologist and two advanced midlevel epilepsy practitioners.

2.2. Questionnaire

The questionnaire was administered anonymously via Research Electronic Data Capture (REDCap) [16], a secure web-based application

hosted at the University of Nebraska Medical Center. The questionnaire took approximately 10 min to complete. To minimize investigator bias, participants who had given consent were provided with an iPad or laptop and asked to complete the survey in a private setting without presence of staff. The questionnaire was compiled of 29 questions which were organized in the three sections. Specifically, the first section was focused on demographic characteristics and disease-related information, including seizure semiology, utilization of anticonvulsants, and time from the last seizure. The second section was designed to clarify participants' driving history, driving behavior, and awareness of relevant restrictions, including driving against medical advice and communicating personal seizure status to the treating provider. The third section assessed participants' perceived barriers to alternative transportation and determined the social impact of driving restrictions. The survey is enclosed in Appendix A. Several questions were adapted from the previously published survey-based studies on driving behavior in persons with seizures [9,17]. The study was approved by the institutional review board of the University of Nebraska Medical Center.

2.3. Data analysis

The respondents were residents of the three surrounding states: Iowa, Oklahoma and Nebraska. The Iowa and Oklahoma state regulations restrict driving for 6 months after the last seizure, and there is no mandatory physician reporting of epilepsy to the governing authorities [18]. The duration of abstinence from driving in epilepsy is not established by the state of Nebraska, but it is determined by treating physician; residents of Nebraska treated at our epilepsy center are advised to abstain from driving for at least 3 months after the last seizure [18]. The responses regarding the knowledge of the driving restrictions were considered correct if both the state of residence and the duration of driving restriction were listed correctly (i.e., 6, 6, and 3 months for Iowa, Oklahoma, and Nebraska, respectively).

Descriptive statistics were calculated for the affirmative and negative responses to the specific questions separately for the PG and AGs. Associations between patient groups and categorical variables were tested using Fisher's Exact tests, and differences in continuous variables between the two groups were analyzed using Wilcoxon Rank Sum tests, using SAS software version 9.4 (SAS Institute Inc., Cary, NC).

3. Results

3.1. Comparison of demographic characteristics and seizure history between AG and PG

Seventy-one participants who satisfied the inclusion criteria were enrolled in the study. All participants included into the survey were formally diagnosed with seizures by their epilepsy care providers. Nevertheless, for unclear reasons, two (4%) participants from the ambulatory care group did not answer affirmatively when being asked whether they carry a confirmed diagnosis of seizures. There were 46 (65%) respondents in the AG and 25 (35%) respondents in the PG. The AG was comprised of 21 (46%) women and 25 (54%) men, while the PG consisted of 14 (56%) women and 11 (44%) men (Fig. 1). There was no significant difference in the median age of the AG (33 years) and PG (46 years; $p = 0.47$). The total number of responders who resided in the states of Nebraska, Iowa, and Oklahoma were 48, 12, and 1, respectively; information about state of residence was missing in 10 completed questionnaires (14%); the distribution of AG and PG participants was not significantly different across the states of residence ($p = 0.38$). The employment rates were significantly higher in the AG compared with the PG ($p = 0.04$). Specifically, employment was maintained by 34 (75%) of respondents in the AG and only 12 (48%) of those in the PG (Fig. 1).

Of the 71 responders who completed the questionnaire, 62 (87%) reported seizure-related alteration of awareness, and 49 (69%) stated

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