

Safer Mobility for Epileptics in the United States

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Social Impact

Epilepsy, a brain disorder characterized by seizures, affects the everyday lives of about 2.7 million Americans. Twenty to thirty percent of patients continue to experience seizures despite current treatments, making it unsafe for them to drive a vehicle. In twenty-first century America, driving can be a practical necessity. Epileptics sometimes respond to this by driving despite their condition. Current legislation does not adequately address the needs of epileptics who cannot drive. A properly implemented solution consisting of improved legislation, alternative transportation programs, and education would improve epileptics' quality of life and safety for everyone on the road.

“Epileptics are putting themselves and others at risk by driving illegally”



Biography

Diana Burk is a fifth-year biomedical engineering and neuroscience double major. Although a Virginia native, she transferred from Northwestern University to U.Va after her first year of college and will graduate in May with the class of 2011. She strives to be a link between basic science and engineering through her coursework and research. Last year she was a member of the first place team at the Undergraduate Research and Design Symposium (URDS). The Capstone team designed a catheter implant for controlling epileptic seizures. She individually pursued the impact of epilepsy on driving for her social thesis to fulfill the requirements of the engineering major. She is currently studying shifts in brain cell density in epilepsy for her distinguished major thesis in neuroscience. A former member of the U.Va cross-country and track and field team, she also enjoys athletic endeavors and believes that a strong body reflects a strong, inquisitive mind. Her peers recently honored her by inducting her into the Raven Society. In fall 2010, she will start a four-year Ph.D. program through the Howard Hughes Medical Institute Janelia Farm and the University of Cambridge in the U.K. She will be studying how the human brain controls movement with robotic interfaces and biological methods.

Abstract

Epilepsy affects over 50 million people in the world, including 2.7 million Americans. Due to inadequate public transportation and alternatives to driving in a society where driving plays a key role in economic self sufficiency and freedom, epileptics are putting themselves and others at risk by driving illegally. Epileptics sometimes respond to the social pressure to continue driving by hiding the severity of their condition to avoid license suspension or driving with an invalid license. Alternatives must be provided for those who cannot ever drive and for those who are temporarily suspended from driving in order to increase road safety. A review of current methods used to promote driving safety shows a clear possibility for the design of such alternatives. Proposed here is a three-part solution that builds on the strengths of current programs against drunk driving. The three-part solution focuses on consistent legislation, alternative transportation programs, and education to improve road safety. These recommendations aim to improve the integration of epileptics into the sociotechnical system of driving, improve road safety and epileptics' quality of life.

Introduction

Epilepsy affects the everyday lives of millions of Americans. One in 100 Americans has the condition. Epilepsy is a brain disorder in which groups of neurons malfunction and cause seizures, which are episodes characterized by convulsions, muscle spasms, and/or alterations of consciousness. For many patients, seizures can be controlled with drugs or surgical removal of the seizure-causing brain region. However, 25-30% of patients continue to experience seizures despite current treatments, which is known as having intractable epilepsy (Epilepsy Foundation, 2009). A health survey revealed that 36% of adults with active epilepsy are physically disabled or unable to work (Blackwell, 2007). A strong correlation was established between mood disorders, poor general health, and seizure frequency in patients who are unresponsive to medications: 20-30% of epilepsy patients do not respond to current medications (Epilepsy Foundation, 2009). The diverse challenges of living with epilepsy depend on factors such as age and disorder severity. Epileptics sometimes find it difficult to work at certain occupations, drive a car, participate fully in school, or form relationships. Stigma against epileptics is cross-cultural, as it is pervasive in countries such as Nigeria, Austria, Korea and the United States (Onwuekwe et al., 2009; Spatt et al.; 2005, T.F. Hung, 2009; Baruchin, 2008). Epileptics experience stigma from childhood through adulthood in a variety of environments (Baruchin, 2008). It is necessary to investigate how common sociotechnical systems exclude epileptics from society or integrate them into it. A review of current structural, legal and social mechanisms used to promote driving safety will support recommendations for the better integration of epileptics into the sociotechnical system of driving to improve road safety and epileptics' quality of life.

In twenty-first century America, driving can be a practical necessity. This social fact is of special significance to epileptics. Epileptics subject to uncontrollable seizures threaten the safety of everyone near them on the road when they drive; however, because the number of deaths per year from seizure-related car accidents is lower than from alcohol-related accidents, the risk is highly underappreciated (Richards, 2004). By raising awareness for both the implications of the condition and the risks for epileptics and non-epileptics, road safety could be greatly improved. Social factors influence the integration of epileptics in society and thereby influence their quality of life. Of the estimated 50 million people who have epilepsy, most experience social side effects of the disorder. Epileptic patients are capable of living normal, healthy lives and having successful relationships. However, patients often experience severe ostracism, social stigma, or limitations by sociotechnical systems. Epileptics can have a difficult time finding a job or staying employed; this is indicated by a correlation between unemployment and seizure frequency. A survey of 1,341 epileptics with variable seizure frequency showed a strong negative correlation between seizure activity and full- or part-time employment status and a strong positive correlation between seizure activity and unemployment (Jacoby et al., 1996). An economic study of correlations between costs and seizure frequency conducted through general practices, university hospitals and epilepsy centers gave similar results. The patients from the epilepsy centers had the highest unemployment rate, lowest quality of life test scores, and highest seizure frequency (Kotsopoulos et al., 2003).

Self-reporting versus mandated reporting

Epileptics' difficulties with employment often stem from a larger problem: a lack of available transportation to and

from work. Inadequate public transportation in some cities hinders epileptics who cannot drive, which limits where epileptics can work and live. Surveys reflect that this inconvenience has caused up to 90% of epileptics to leave their condition undisclosed to the Department of Motor Vehicles (DMV) in order to receive or keep their license (Salinski et al., 1992). Reporting policies and DMV testing vary between states. Doctors in six states (CA, DE, NV, NJ, OR, PA) are required to report their patients' data to the local DMV; this mechanism is designed to bypass patients' refusals to report their condition (Aschkenasy et al., 2005). A survey of patients at two adult seizure clinics demonstrated that a strict physician reporting policy would likely cause more epileptics to not report their condition to their doctors and would also depreciate the doctor-patient relationship. Ninety six percent of patients stated they would inform their physician and 56% would report to the DMV if doctors were not allowed to report patient information directly. However, only 84% of the total surveyed population and 72% of the driving patient population would inform their physician if physician reporting were required. Nine to 17% of driving patients stated they would continue to drive with a suspended license if physician reporting were enacted (Salinsky et al., 1992). This is dangerous for epileptics who could fail to receive treatment, and for non-epileptics who could be harmed by the consequences of an unexpected seizure on the road. A reporting system that promotes a moral obligation of self-reporting could drastically reduce the risk of these accidents. In addition, by providing alternative transportation for those who self-report, epileptics would feel less of a strain on their daily lives and, as a result, may have an improved relationship with their health care provider.

Restrictive laws do not increase patient compliance

Completely banning epileptics from driving does not appear to be a solution. In Japan, epileptics are completely prohibited from driving. Despite having access to a public transportation system known for punctuality and efficiency, epileptics often acquire illegal driver's licenses. A survey of 3,522 people with epilepsy throughout Japan showed that 48.6% held an illegal driver's license and 38.9% actually drove. The automobile accident rate was 9.6% for patients with uncontrolled seizures and 5.3% for those with controlled seizures (Takeda et al., 1992). Seizure frequency and severity correlated with the license-holding rate. Those with more severe seizures were less likely to hold a license, showing some personal responsibility for safety among the patients. A similar study conducted in the United Kingdom revealed that 8% of 106 patients had driven illegally. In the U.K., some epileptics with controlled seizures are allowed to drive. However, the restrictions placed on epileptics are inconsistent, which has led to confusion among epileptics, especially among patients who cannot currently drive but wish to do so in the future and would likely be

eligible after treatment. This survey revealed the importance of variable restriction based on type and severity of seizures, the presence of an identified trigger, and seizure frequency. The lack of understanding among patients and consistency of current restrictions were the main reasons given by patients for driving illegally (Dickey et al., 1993). Laws requiring epileptics to disclose their condition have not been successful in New Zealand and Canada. Fifty seven percent of New Zealand drivers with epilepsy and 51% in Canada did not disclose their condition to the government (Stanaway et al., 1983; Vander Lugt et al., 1973). One of the most common suggestions given by patients in Dickey's British study for improvement of driving legislation was more personalized restrictions. A general ban diminishes compliance of epileptics to driving laws. Why do epileptics feel the need to drive despite their condition? Research shows that the American population in general is driving more and epileptics are not excluded from this shift. It is no surprise that people are driving more often as years pass. According to the Federal Highway Administration, the kilometers of vehicle travel on U.S. roads has increased 2.7% per person per year since 1970 (Handy, 2002). A detailed survey of 43 American drivers revealed that 10% drive more than they need to, but almost 100% believed that driving was necessary, gave them freedom and convenience and fostered their social lives (Handy et al., 2005). In Germany, researchers found an increase in epileptics holding driver's licenses, from 27% in 1967 to 50% in 1990 (Thorbecke, 1991). The most common reasons for epileptics driving illegally were reported to be going to work, shopping and recreation (Takeda et al., 1992; Handy et al., 2005). This shows the response of epileptics to a general increased necessity to drive.

A link between alcohol-related and epilepsy-related traffic concerns

Epilepsy-related traffic concerns are analogous to many alcohol-related traffic concerns. The convenience of driving and the perception of it as a necessity are reflected by those who choose to drive under the influence of alcohol. Although alcohol impairs driving ability and DUI is a serious legal violation in every state, many people drive under the influence. A survey of 3,388 DUI offenders suggests that the most common time of arrest is between 9pm and 3am on Saturdays. Sixty percent of respondents reported that they lived less than two miles from their departure place, demonstrating that the perceived risk of a short trip was low (Evalcorp, 2008). However, in a survey of 213 epileptics, 19% reported that to protect their driving privileges, they were dishonest about their seizure frequency, but 53% believed that epilepsy made a car accident more likely. Researchers concluded from this study that, unlike drunk drivers, epileptics perceived the risk as high, and that most epileptics accept the risk for occupational purposes (Elliott et al.,

2008). Nevertheless, current legislation in the United States treats the two populations quite similarly. An arrested drunk driver and an epileptic whose seizures become uncontrolled will both have their licenses suspended. Yet legislation does not provide a means whereby epileptics can avoid this loss at a manageable cost in terms of convenience. Designated drivers, safe ride programs and some taxi companies often provide transportation at discounted rates for people who plan to drink starting at peak hours or during large celebrations. One research group in Spain identified eleven types of prevention, including venue-centered, community, law enforcement, and industry support programs (Calafat et al., 2009). However, no such programs target the needs of epileptics who more often drive for occupation than recreation. Social marketing campaigns aim to prevent drunk driving, but no public campaigns exist to prevent driving with epilepsy. Many social marketing campaigns promote particular messages about drunk driving and safety. These campaigns are intended to increase the perceived severity of the threat, its probability of occurrence, and drivers' perception of self-efficacy to avoid driving drunk. Drivers receive a powerful message that their decisions can prevent drunk driving. This was shown to decrease the prevalence of alcohol-related crashes. Such campaigns have also been linked to an increase in social disapproval for drunk driving (Cismaru et al., 2009). No known campaigns, however, attempt to show the risks of driving with epilepsy with such vigor. This raises an important difference between how legislation has chosen to address the risks of a recreational choice, such as drunk driving, but not a lifetime condition, such as epilepsy. However, despite the difference in the nature of the issue, similar methods used in the drunk driving campaign could be used to raise awareness about the risks of epilepsy. This is discussed in further detail in the proposed solution. Current legislation does not appear to be effective in keeping epileptics with uncontrolled seizures from driving. Epileptics need a means to the same freedom to travel as non-epileptics; therefore legislation should shift to provide more options for those who cannot drive. Given the importance and perceived necessity of driving in the United States, epileptics will continue to seek a way to continue driving regardless of the risks and the law. While education to promote awareness and discourage epileptics from driving illegally might help increase social disapproval for illegal driving, a multi-faceted approach will be necessary to gain compliance of the vast majority of epileptics.

Personal Accounts About Driving and Epilepsy

The inability to drive is more than a matter of inconvenience for epileptics. Epileptics often report feeling foolish for having to constantly be shuttled around by their friends and family, and feel like an imposition (Bornemann, 1994; Barden, 1999). Many also end up missing job deadlines, dates, and other social events because they cannot drive (Seizures and

Driving, 2010; Bornemann, 1994). Riding public transportation takes time and money and is not always an option for certain times and locations of travel. Public transportation can almost never provide the door-to-door convenience of personal transportation. Many adolescent epileptics feel that their social lives are stunted by their inability to drive. Social activities, such as sports and dating, are more difficult to manage when they must rely on others for transportation. Almost all personal stories from epileptics mention a loss of freedom, independence and an emotional toll from the inability to drive (Bornemann 1994; Barden 1999; Seizures and Driving, 2010). One epileptic blogger wrote, "I will never have complete independence again," after having her license suspended for having a seizure. Her notification letter stated that she must have a letter from her neurologist, a CAT scan, an electroencephalogram (EEG), be seizure-free for an implicit time period, and be taking a medication that is on an approved safe list at the time she reapplies for her license. She also noted her frustration with the fact that alcoholics and elderly people with visual disability are less likely to lose their license and have an easier time regaining their license following a suspension (My License, 2009). These personal accounts demonstrate that an effective solution must provide an alternative to driving and fair legislation to reduce the frustration that is compromising compliance with the law.

A Three-Part, Proportionate and Individualized Solution

The Centers for Disease Control and Prevention reported that about 1% of the American adult population has epilepsy (CNN, 2008). A program to help these millions of people stay safe on the roads could prevent 86 deaths per year due to seizure-related automobile crashes (Richards, 2004). Countries have tried legislation to prohibit sub-populations of epileptics from driving. However, these methods have not had success in promoting patient compliance and thus the avoidable risks associated with driving and epilepsy previously described, still remain. The solution must be proportionate and sufficiently reasonable to maximize compliance, and it should empower epileptics to self-report. An alternative to driving must also be provided for those who cannot drive. The goal is to revamp the relationship between epileptics and driving such that all parties are aware of the condition and appropriate precautions are taken to optimize both road safety and the quality of life of epileptics.

Consistent legislation & mandated physician reporting

Epileptics report that one of the most aggravating things is the required seizure-free period, which varies (Bornemann 1994; Barden 1999; Seizures and Driving, 2010). Epileptics also express frustration with the lack of distinction between severe and controlled epilepsy. While the law gives more privileges to those with controlled epilepsy, it does not

recognize the different seizure triggers that can make the difference between an epileptic who can drive safely and an epileptic who cannot. The law could be based on epilepsy severity rather than on state of residence. For example, the type of epilepsy a patient has, their seizure triggers, and the full seizure history could be used to determine the required seizure-free period for license renewal. Research is needed to determine the seizure-free periods necessary to ensure safety given a certain type of epilepsy and mandated physician reporting. Feedback from patients on the side effects of medications and the types of seizures could also help regulations classify epileptics who should be cleared to drive.

For safety, all states should require physician reporting of epilepsy. Mandated reporting puts the patient, the physician, and DMV on the same footing. However, surveys show that mandated physician reporting alone could compromise the patient-physician relationship (Salinsky et al., 1992). Punishment alone, such as license suspension, does not keep epileptics from finding a way to drive. To work, stricter reporting rules must be accompanied by alternatives to driving so that those who cannot drive have attractive alternatives to driving illegally. A mechanism to discourage concealment of epilepsy and strong incentives for self-reporting are needed. The physician needs to feel responsible for getting the information from the patient through regular check-up exams and EEG recordings. To design effective incentives and punishments, researchers must study epileptics' behaviors and motivations.

Providing alternatives to driving

Programs intended to prevent drunk driving have been successful. Safe ride programs can reintroduce convenience to transportation, as these programs normally provide door-to-door service. While it would be difficult to instate a full-time safe ride program for the 1% of the American population with epilepsy, a safe ride program for epileptics whose licenses have been temporarily suspended might be feasible. A temporary employment program could give commercial drivers an alternative to lying about their condition or losing their job. A third possible program for children of parents with epilepsy could significantly reduce the stress on parents to hide their condition. Parents may fail to report seizures out of fear that their children's mobility will be constrained. This puts the children, parents, and other drivers at risk, and this risk could be prevented through an after-hours driving program. These alternative programs could help alleviate the factors inducing epileptics to find a means of driving illegally. Researchers should determine the best means of implementing these programs within a reasonable budget. Increased awareness of the risks of epilepsy and driving is also required to gain widespread support for these programs.

Raising awareness through the media and education

An effective solution must make everyone more aware of the risks of driving with epilepsy such that epileptics are motivated to self-report and that non-epileptics are supportive. In 1988, the Harvard Alcohol Project started to bring "designated driver" into everyday vocabulary through clever use of popular media programs. Writers of popular TV shows agreed to use the term "designated driver," and allude to the risks associated with drunk driving in their scripts. Popular news programs also aired public service announcements expressing the same message. The program resulted in a four-year decline of 24% in annual alcohol-related traffic fatalities (Harvard Center for Health Communication, 2010). This technique could be employed to raise awareness for the risks of driving with epilepsy. Current awareness programs regarding epilepsy, such as road races and promotional events, are for the condition and for research, and never address the risks of driving. Media campaigns and awareness events promoting the particular message of safe driving with epilepsy could foster a moral norm among epileptics to self-report. These concepts should be integrated into the children's education to propagate this awareness more effectively.

Conclusion

Current legislation and programs do not adequately address the needs of epileptics who cannot drive. Thus epileptics are finding ways of driving regardless of license suspensions, laws, and perceived risk. A properly implemented solution consisting of improved legislation, alternative transportation programs, and education would improve road safety. The solution must incorporate scientific research and patient feedback. New programs could be tested in small areas and states before scaling up nationwide. The ultimate goal would be consistency across the country such that epileptics receive equal treatment regardless of their state of residence. This multi-faceted solution would increase awareness of the dangers and struggles of driving with epilepsy, thereby improving integration of epileptics into everyday society.

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Works Cited

- Aschkenasy, M., Drescher, M., & Ratzan, M. (2006). Physician reporting of medically impaired drivers. *Journal of Emergency Medicine, 30*(1), 29-39.
- Barden, S. (1999). Against all odds- a personal account of epilepsy. *Seizure, 8*, 272-276.
- Baruchin, A. (2008, May 16). Easing the seizures, and stigma, of epilepsy. *The New York Times*. Retrieved from <http://health.nytimes.com/ref/health/healthguide/esn-epilepsy-ess.html>.
- Blackwell Publishing Ltd. (2007, October 30). Quality of life study examines burden of epilepsy. *ScienceDaily*. Retrieved September 22, 2009, from <http://www.sciencedaily.com/releases/2007/10/071029130925.htm>.
- Bornemann, M. (1994). Viewpoint of a driver with epilepsy. *Epilepsia, 35*(3), 665-667.
- Calafat, A., Juan, M., & Duch, M. (2009). Preventive interventions in nightlife: a review. *Addiciones, 21*(4), 387-413.
- Cismaru, M., & Lavack, A. (2009). Social marketing campaigns aimed at preventing drunk driving: a review and recommendations. *International Marketing Review, 26*(3), 292-311.
- CNN.com. (2008). Survey estimates 1 percent of adults have active epilepsy. CNNhealth.com. Retrieved February 20, 2010 from <http://www.cnn.com/2008/HEALTH/conditions/08/08/epilepsy.adults/index.html>.
- Dickey, W., & Morrow, J. (1993). Epilepsy and driving: attitudes and practices among patients attending a seizure clinic. *Journal of the Royal Society of Medicine, 86*(10), 566-568.
- Harvard Center for Health Communication (2010). Harvard alcohol project. Retrieved from: <http://www.hsph.harvard.edu/research/chc/harvard-alcohol-project/>.
- Elliot, J. & Long, L. (2008). Perceived risk, resources, and perceptions concerning driving and epilepsy: a patient perspective. *Epilepsy & Behavior, 13*, 381-386.
- Epilepsy Foundation of America. About epilepsy- treatment options: medications. Retrieved September 22, 2009 from: <http://www.epilepsyfoundation.org/about/treatment/medications/index.cfm>.
- Evalcorp Research and Consulting. (2008). DUI offender survey report-2008. *Montana Community Change Project*. Retrieved February 19, 2010 from: http://www.mtccp.info/documents/DUIOffender-SurveyReport_April2009_Final_000.pdf.
- Handy, S. (2002). Accessibility v. mobility-enhancing strategies for addressing automobile dependence in the U.S. European conference of ministers of transport, Paris.
- Handy, S., Weston, L., & Mokhtarian, P. (2005). Driving by choice or necessity? *Transportation Research, 39A*(2-3), 183-204.
- Jacoby, A., Baker, G., Steen, N., Potts, P. & Chadwick, D. (1996). The clinical course of epilepsy and its psychosocial correlates: findings from a U.K. community study. *Epilepsia, 37*(2), 148-161.
- Kobau, R. & Price, P. (2003). Knowledge of epilepsy and familiarity with this disorder in the U.S. population: results from the 2002 health-styles survey. *Epilepsia, 44*(11), 1449-1454.
- Kotsopoulos, I., Evers, S., Ament, A., Kessels, F., Krom, M, et al. (2003). The costs of epilepsy in three different populations of patients with epilepsy. *Epilepsy Research, 54*, 131-140.
- Langfitt, J.T., & Westerveld, M. (2007). Worsening of quality of life after epilepsy surgery. *Neurology, 68*(23), 1988-1994.
- My License. (2009). Coping-with-epilepsy.com. Retrieved from: <http://www.coping-with-epilepsy.com/forums/f36/my-license-7841/3>.
- Onwuekwe, I.O. & Onodugo, O.D. (2009). Pattern and presentation of epilepsy in Nigerian Africans: a study of trends in the southeast. *Transactions of the Royal Society of Tropical Medicine and Hygiene, 103*(8), 785-789.
- Richards, K. (2004). The risk of fatal car crashes in people with epilepsy. *Neurology, 63*(12), E12-E13.
- Seizures and Driving (2010). Coping-with-epilepsy.com. Retrieved from: <http://www.coping-with-epilepsy.com/forums/f34/seizures-driving-8489/>.
- Spatt, J., & Bauer, G. (2005). Predictors for negative attitudes toward subjects with epilepsy: a representative survey in the general public in Austria. *Epilepsia, 46*(5), 736-742.
- Stanaway, L., Johnson R., & Lambie, D. (1983). Epilepsy and driving. *New Zealand Medical Journal, 96*, 525-528.
- Takeda, A., Kawai, I., Fukushima, Y., Yagi, K., & Seino, M. (1992). Epilepsy and driving in Japan: current status as investigated in a prospective society. *Journal of Epilepsy, 5*, 135-139.
- T.F. & Hung, A. (2009). Psycho-social impact of epilepsy and issues of stigma. *The Hong Kong Medical Diary, 14*(5), 15-17.
- Thorbecke, R. (1991). Epilepsy and driving license in the federal republic of Germany and other European countries. *The Japanese Journal of Psychology and Neurology, 45*(2), 313-317.
- Van der Lugt, P. (1975). Is an application form useful to select patients with epilepsy who may drive? *Epilepsia, 16*, 743-746.