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Driving People with Epilepsy Away from Stigma

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COLUMN ARTICLE

Driving and Medical Issues

Already in the late sixties Grattan and Jeffcoate [1] stated that "*considerable amount of research has been done, and is being done in various countries in an attempt to elucidate more accurately the part that medical factors may or may not play in the causation of road accidents*".

Nowadays free mobility is broadly accepted as a basic human right and driving is often considered a key component of modern life. However, when medical conditions impair fitness to drive, driving becomes a serious, complex and sensitive issue, as restrictions are impinging upon independence, employment, socioeconomic status and quality of life [2,3].

It is well-known that epilepsy impacts on people's ability to be eligible to drive safely. After the initial diagnosis, the type, frequency and predictability of seizures directly affect the chances of a person with epilepsy obtaining or retaining a driver's license/permit, which is listed as a major concern by people with epilepsy (PWE) in relevant surveys [4].

Epilepsy and Driving restrictions

Through the years, epilepsy has attracted prejudice, stereotype, and stigma, factors that go beyond its medical frame. These factors function as barriers for PWE towards establishing social contacts and relationships and make them skeptical on their sensitive personal data [5]. If transport is an integral part of everyday routine (for employment or family needs), being deprived of a license after diagnosis of epilepsy or a seizure can disrupt a person's entire life, stressing person and family as well and stigmatizing the person for not being able to perform as other people can. However, early studies concluded that license deprivation can be temporary as after a demonstrated period of seizure free living individuals could safely return to the road. In this context, reasonable opportunities to individuals with epilepsy to drive are possible through appropriate legal requirements. On the other hand, the debate on expanding driving legislation and standards, on individual and public safety over the individual's right to drive is an on-going one [6].

Finding the balance between individual rights and public safety is quite a challenge. If restrictions are believed to be unnecessarily burdensome, they may not serve their cause and result in low rates of doctor counseling and reporting, as well as in noncompliance with driving regulations. These last vary widely in the western world and literature comments on the heterogeneity and the complex nature of legislation surrounding driving and PWE [7,8]. Of course, regulations are necessary and their primary aim is to maximize public safety, that is, protect other road users rather than to safeguard the driver [9], whilst preserving

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individual freedom of PWE as much as possible [10]. This freedom is threatened by excessive restriction which may provoke non-responsible behavior like non-compliance [11] or under-reporting of seizures by patients [12].

Medical Advice and Compliance

Responsible behavior involves doctor consulting and self-discipline about the respective medical guidelines. However, epilepsy and driving is a delicate issue that may risk the doctor–patient relationship impacting on treatment and bringing about secrecy and risk of even fatal nature for the patient or other road users [13]. Given the tendency for non-compliance, there is a long debate about voluntary and mandatory reporting. Should a patient ignore medical suggestion not to drive, doctors are faced with the dilemma to breach patient confidentiality and disclose information to the appropriate authorities for the interest of public safety.

People with epilepsy ignoring medical advice make no exception when it comes to the human impulse to ignore actual or perceived restrictions to their personal freedom, e.g. speed or alcohol limits violations. Without underestimating the risk in driving with epilepsy, it has to be reported that comparative research has shown the accident ratio rate for drivers with epilepsy to be far lower than for young drivers, older drivers and sleep-deprived drivers or those having consumed alcohol within the legal limit. However, it needs to be stretched that the community and licensing authorities accept the accident ratio rates for all the other groups except for persons with epilepsy [4], which raises the case of discrimination.

Meeting the non-compliance of patients

As in many cases of health issues, there is a number of people with epilepsy that drives illegally, due to emotional and logistical concerns of immobility and dependence. It is this non-compliance with rules for driving that should be addressed by targeting patients and providing them with understandable information of the risk [4]. Patients no longer holding driving privileges as a result of driving laws need also to be provided with alternatives for their mobility needs. Decision-makers need to consider public transport solutions or demand responsive transportation systems tailored to patients' needs to ensure safe mobility for people. Doctors awareness should also be enhanced in order for them to educate patients about aspects which impair driving, and be attentive to increases in disability over time. A multidisciplinary approach should be adopted to cover all components of safe mobility of PWE, considering also essentially the important role family members can play in developing strategies for patient safety and welfare [14].

Literature is being currently enriched on several aspects of the interface of driving and epilepsy. Questions related to mandatory or self-reporting of seizures, issues like doctors' responsibilities and patients' self-discipline (meaning compliance to medical guidelines), as well as the formulation of efficient regulations face a growing concern within the research community. Future research and public policy should address knowledge gaps in driving risks for PWE and deficiencies in regulations. Sustainable mobility promotion should also involve vulnerable groups like PWE who are in need of good and reliable alternatives to driving a car. Epilepsy organizations and qualified professionals need to come up with evidence-based guidelines so as to strongly advocate on behalf of PWE to improve regulations balancing safety enhancement and the welfare of persons with epilepsy. National driving authorities, motor insurance companies and police can also give their input in the effort to minimize risk. Of course, it is likely that deficiencies in the recognition of events, in counseling and in compliance will remain.

Discrimination and Social Marketing Contribution

One of psychosocial consequences of epilepsy is a change in PWE social inclusion [15], meaning, in participation, capacity development, and societal welfare increase [16]. Mlinar., *et al.* (2016) inform on past research focusing on individual aspects of epilepsy and their effect on PWE quality of life, pointing out the lack of studies on PWE social inclusion and that discrimination and stigmatization affect PWE more than epileptic episodes [17]. Another significant effect of epilepsy is the loss of autonomy and dependence on others, which are psychosocial burdens. So, it is important to enhance awareness and support of PWE.

Social marketing can be beneficial to help PWE individually as well as to positively affect public attitude towards

PWE [18]. PWE need to be informed, so they will be able to address the consequences of epilepsy. Secondly, PWE's family and friends have to be informed of epilepsy to be able to share in the life of PWE, understand them, and react appropriately when or if epilepsy deteriorates. Last but not least, broader society needs to be aware of epilepsy, since their attitude influences how PWE experience epilepsy and its consequences. Media and other campaigns that aim to raise awareness of epilepsy have proven to be relatively effective, even more so if they included PWE.

There remains considerable room for improving everyday life of PWE and investing in driving issues through an interdisciplinary approach. Medical issues should advance and so should regulations. Transportation scientists working on road safety issues should get informed about new categories of vulnerable users and the promoted permissive road environment should include measures to meet all drivers needs. Doctors, psychologists and mobility scientists should cooperate with driving and other authorities in order to commonly shape a social marketing approach. This last will target multiple groups, from authorities and medical world, PWE and families to broad public, so as to raise awareness and it is a social necessity to drive people away from stigma, encourage responsible behavior and public acceptance [19-21].

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