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A Systematic Review Examining Conflicting Attitudes Around Safety and Legislation Towards People Driving with Epilepsy

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Abstract: Road crashes that have been caused by epilepsy seizures have led to changes in perceptions about people driving with epilepsy. **Objective:** By carrying out a review of the studies that have been conducted in this area, these conflicting attitudes towards people driving with epilepsy can be summarised. **Study Design:** A comprehensive and systematic review of the available literature was conducted. **Methods:** Using PubMed, PsychINFO, Science Direct, PROSPERO, Cochrane Database of Systematic Reviews and included hand searches of reference lists within relevant papers and narrative reviews. **Results:** Nine studies met the inclusion criteria and examined the attitudes of professionals, individuals with epilepsy and the general public on driving behaviour among individuals with epilepsy. Results identified a difference in opinion about driving with epilepsy; individuals felt that driving played a big part in them living independently and were willing to drive against legislation in order to continue travel. The more experienced a physician within the area of epilepsy, the more lenient their views with regard to legislation on driving with epilepsy. **Conclusions:** This review highlights the importance of finding ways to increase the perceived susceptibility and severity of driving with uncontrolled seizures to maintain road safety and the need for further education on this topic. This in turn would reduce car crashes associated with epilepsy and reduce the associated stigma.

Keywords: Systematic Review, Attitudes, Behaviour, Driving, Epilepsy

1. Introduction

Individuals with epilepsy can lead normal and healthy lives [1], however, in 1970, individuals with epilepsy were prohibited from driving [2] and many countries still restrict people with epilepsy from driving today [3]. UK legislation states that each time a person has a seizure, they must surrender their license and be seizure free for one year before re-applying [1-4]. Epilepsy seizures can cause some road traffic accidents and fatalities [5] and it has been reported that people with epilepsy have a crash rate 1.4 times that of the general driving population [6]. However, previous research confirmed risk of crashes caused by people with epilepsy is not significantly higher than for those with other chronic medical conditions such as heart disease [7]. Crashes

caused by people with epilepsy are mainly due to drivers who do not comply with regulations and continue to drive despite having seizures [7]. According to research [7] almost one fifth of individuals with epilepsy are likely to continue to drive when told not to and are dishonest about their seizures in order to continue driving. Over a quarter of individuals with epilepsy have reported having a car accident due to a seizure and a fifth of individuals with epilepsy continue to drive, despite poorly controlled seizures [7]. It has also been found that a considerable proportion of individuals continue driving despite uncontrolled seizures [8] and a major reason for this is for individuals to get to work [7]. In Greece, it has been reported that over one third of individuals admit to driving when they know they should not [9], however, this finding should be interpreted in context with the licensing standards used for that country.

Road traffic accidents that have been caused by epilepsy seizures have led to inconsistent perceptions coming from various groups about their opinions on driving with epilepsy. Health professionals have voiced how essential it is to review current legislations for driving with epilepsy [10]. A number of negative attitudes from the general public have been reported, thus causing discrimination against people with epilepsy [11-12]. This could be due to a lack of knowledge about epilepsy or false beliefs about the effects of the condition [1]. However, driving is an important part of the lives of people with epilepsy [1] and despite this, negative attitudes have led to some feelings that all people with epilepsy should not drive [11]. Furthermore, compared with neurologists, non-specialist physicians have been reported to hold restrictive beliefs about individuals with epilepsy driving [13]; however, one study with Australian neurologists and general practitioners found the former were more lenient in their views about driving legislation [13].

Research has highlighted a need for cooperation between driving authorities and doctors for further amendment of regulations and a reduction in the stigma attached to driving with epilepsy [14]. It is clear that some people with epilepsy may continue to drive despite having regular seizures [15], however people who drive legally with seizures under control should not be discriminated against [11]. There are differences in opinion about driving with epilepsy between health professionals and people with and without epilepsy [10, 11, 14]. This highlights the importance of conducting a review to summarize and draw comparisons between these differing perceptions and attitudes [10, 11, 14]. The results of this review could assist the understanding of how attitudes can affect people with epilepsy but also pre-empt possible prevention methods for dangerous driving with epilepsy in the future [15]. The specific aim of this review was to identify current understanding and differing opinions of people with epilepsy; health professionals; and the general public on epilepsy and driving behavior.

2. Method

2.1. Eligibility Criteria

To fulfil the purpose of this review, studies were included if they met the following criteria:

1. Investigated individuals perspectives on driving with epilepsy.
2. Full length studies published in peer reviewed journals.
3. Primary studies using retrospective or prospective designs.

Studies were excluded if:

1. The primary focus was not driving with epilepsy.
2. Does not include perceptions or beliefs of either individuals with epilepsy, health professionals or people without epilepsy on driving.
3. Studies of individuals with epilepsy under the legal driving age.
4. Commentaries, editorials and case studies.

2.2. Search Strategy

Subject specific databases (PubMed, PsychINFO, Science Direct, PROSPERO and the Cochrane Database of Systematic Reviews, Epilepsy Action, Epilepsy UK and Epilepsy Society) were systematically searched. Each database was searched using the following search terms and combined with Boolean operators: 1. Perceptions; 2. Attitudes; 3. Belief; 4. Thoughts; 5. Judgement; 6. Judgment; 7. #1 OR #2 OR #3 OR #4 OR #5 OR #6; 8. Epilepsy; 9. Seizures; 10. Convulsions; 11. Absences; 12. Fits; 13. #8 OR #9 OR #10 OR #11 OR #12; 14. Driving; 15. Driver; 16. Drive; 17. Vehicle; 18. Car; 19. Machinery; 20. Moving; 21. #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20; 22. #7 AND #13 AND #21. This strategy aimed to maximize the potential of finding all relevant papers. A hand search of reference lists of relevant papers was also performed. The search was conducted in July-August 2016.

2.3. Selection Process

All retrieved titles and abstracts were screened for potential eligibility by the first author. The full text of potential articles was then examined by the same reviewer to determine eligibility for inclusion in the review and these were independently verified by the second author. Any disagreements between reviewers with regard to the eligibility of studies would have been dealt with through discussions between the reviewers; if disagreements could not have been rectified at that stage, then a third independent reviewer would have been appointed. Reviewers agreed that all studies included in the review examined driving and epilepsy with attitudes or perceptions of health professionals/individuals with epilepsy/general public. Data collected from each study included authors (s), country, year published, aim, sample size, study design, key findings and suggestions made by authors.

3. Results

The search produced 4441 potentially relevant papers, 1610 duplicates were removed from the list, leaving 2831 titles and abstracts to be screened, 2822 were excluded because title or abstracts were outside the focus of this review and one article only the abstract was available. Nine full text papers met the inclusion criteria and were reviewed by two independent reviewers. All 9 studies [3, 15-22] examined attitudes towards people driving with epilepsy. A manual search of the reference lists of the 9 studies revealed no further eligible studies for inclusion. It would have been necessary to carry out three separate meta-analyses to identify different perspectives of individuals, professionals and general public. Moreover, as there was high heterogeneity across studies and the global rating of these studies was weak, a meta-analysis was inappropriate for this review [23]. Finally, eight of the nine studies included in this review either used descriptive statistics or frequency data (see Table 1 for a summary of the studies included in the review).

Table 1. Studies included in review.

Study	Research aim	Sample	Design	Data analysis	Key findings	Suggestion
Seneviratne et al, (1998) Sri Lanka	Look at different attitudes of driving with epilepsy	Patients - N=187, Doctors – N=244 Public – N=672	Questionnaires were given to all participants to complete	Descriptive statistics	89.3% physicians believe driving with epilepsy is dangerous 91.8% thought restrictions were necessary Only 13.1% asked their epilepsy patients if they drive 99.7% public believe driving with epilepsy is dangerous 97% should be strict regulations 74.8% believe they should not be driving 94% if they had epilepsy, would not disclose it and continue to drive 95.1% of epilepsy patients – minimal restrictions to increase independence Most accepted it as dangerous	To use attitudes of different groups when designing legislations Doctors to balance independence and safety
Elliott & Long, (2008) USA	To analyse health behaviour attitudes and beliefs in epilepsy to create effective counseling	Patients – N=213, 144 female, 66 male	46-item questionnaire, gathered in 3 ways – posted, given in epilepsy clinic, contacted via email	ANOVA - to compare differences in driving behaviour for demographic variables Logistic regression to predict driving behaviour	88% patients with epilepsy think good health is important and 99% important to improve safety 27% people had car accident due to seizure and had higher perceived susceptibility/severity and lower barriers to changing Lied about driving – more likely to have worse attitudes toward driving and higher barriers to change 7 predictors of behaviour – Caucasian drivers more likely to lie Employed more likely to drive Higher susceptibility/severity of accidents, more likely to lie Higher barriers in drivers	Supporting the need to address health behaviour constructs with counselling epilepsy. Enhancing perceived susceptibility and severity may help change behaviours. Improve awareness of resources and transportation services. Overcoming barriers to change is most difficult – need to inspire.
Dickey et al, (1993) Belfast	Assess attitudes and practices of patients with epilepsy attending a seizure clinic	N=104 patients attending a seizure clinic in Belfast	Questionnaires were given during appointments at the seizure clinic	Descriptive statistics	28% participants eligible to drive during study, 3 patients were driving illegally. 8 had driven illegally before, admitted being told not to but did anyway. 33% could cite the law, but only 41% agree with it. Patients driving legally – only 57% had notified DVLC. Legal restrictions have not helped prevent accidents as compliance decreases	Modification of current regulations might improve compliance and satisfaction among drivers with epilepsy without threat to road safety.
Okumura et al, (2016) Japan	Compared attitudes towards epilepsy and driving before and after exposure to media controversies of car accidents	N= 79 students in 2012 before media controversies N= 90 in 2014 after media controversies – Different participants	Questionnaires given to students studying Health and sport science	Chi square test to compare results from two different dates	Participants became more familiar with epilepsy following media coverage. Positive responses towards epilepsy was higher after media coverage and attitudes towards driving licenses with epilepsy did not differ – 25% should have a license, 37% should not be punished for accidents	Familiarity and attitudes towards epilepsy improved. Increase in punishment for epilepsy drivers if accident caused. Used to help improve public understanding and attitudes towards epilepsy and driving license.
Okumura et al, (2014) Japan	Comparing attitudes towards epilepsy after media coverage of car accidents	N=79 Men = 44 Female = 35 80% knew about epilepsy (group 1) 20% didn't (group 2)	Questionnaire on familiarity and attitudes towards epilepsy and driving	Chi-squared test was used to compare the 2 groups- who know about epilepsy and those who don't know.	25% participants in both groups think that people with epilepsy shouldn't have a license. However, both groups felt that punishment should not be given as a result of an accident. Negative responses to epilepsy were rare. Media coverage did not strongly affect attitude towards driving and epilepsy	Insufficient promotion of the correct information on the relationship between driving and epilepsy. Future studies to focus on the effects of media on knowledge, attitudes and perceptions of epilepsy in public.
Okumura et al, (2015) Japan	To evaluate changes in attitudes of non-medical students about epilepsy and	N=838 student responses, N=310 for before, N=291 for during,	Questionnaires given out prior to a lecture on Health and Sport Science	Chi squared tests were used to compare the rates of positive responses	Rates of positive responses increased even after media coverage. Rates of students understanding epilepsy increased and associated with a decrease in negative response. Improved attitudes did not alter after media coverage reduced. More people knew someone with epilepsy after	The familiarity of epilepsy is increasing in Japan. Distribution of correct knowledge via media can improve people's attitudes towards epilepsy.

Study	Research aim	Sample	Design	Data analysis	Key findings	Suggestion
	driving – before, during and after media coverage of car accidents in epilepsy	N=237 for after			media coverage – can decrease negativity.	Further research needed to decide appropriate methods for distributing knowledge
Okumura et al, (2013) Japan	Compared attitudes towards epilepsy and driving before and after media coverage on car accidents	N=601, N=310 before accident and N=291 after accident	Questionnaires before a lecture on basic knowledge of neurological conditions	Chi squared tests compare the results before and after	Attitudes and familiarity towards epilepsy was improved after media coverage – indicates the importance of spreading correct information on epilepsy	More research needed on a wider public with various backgrounds Improved attitudes towards epilepsy and driving after media coverage – shows importance of increasing public education on epilepsy.
Beran, (1997) Australia	Comparing attitudes between different physicians on driving with epilepsy	N= 19, 4 were not medically trained	Survey given at the First Academic Seminar of the Australian College of Legal Medicine (ACLM)	Descriptive statistics	73.7% physicians believe doctors should report patients driving who may pose a risk 73.7% believe that doctors are not responsible for lost income due to accidents from unreported drivers It is thought there is no absolute answer but safer to report non-compliant driver	Doctors should report non-compliant patients when driving, if unsafe to protect patient and others despite confidentiality breach.
Vogtle et al, (2007) USA	Comparing attitudes and opinions regarding driving in epilepsy between different physicians and neurologists	N=209, family GP – 44%, internal medicine – 27%, neurologists – 24%	Faxed questionnaires to all physicians	Descriptive statistics and X*2 analysis were used to compare physicians and neurologists	No differences between groups on definition of seizure control Family GPs were more likely to oppose license to uncontrolled seizures and neuro Also more likely to agree to set minimum seizure free period before driving Less likely to have patients report seizure related accidents than neuro Physicians with less than 10 epilepsy patients were more likely to oppose license and support mandatory reporting to motor vehicle departments Response bias and lack of respondents	Physicians fail to understand/ support/ interpret driving restrictions – may lead to unnecessary restrictions and can affect QOL. Significant effort in promotion of education of physicians in driving regulations needed.

3.1. Quality Audit

Quality was assessed using the Quality Assessment tool for Quantitative studies [24] as all papers included in this review employed a quantitative approach. Quality was assessed using each component of the assessment tool: selection bias; study-design; confounders; blinding; data-collection method; withdrawals/dropouts. Studies were then rated as strong, medium or weak for each component according to the Assessment Tool and an overall rating of strong, medium or weak. As shown in Table 2, seven of nine included studies received a global rating of weak. All studies, except for one, were rated as weak for data collection due to lack of reliable

or valid questionnaires. The study with a strong global rating used reliable and valid instruments. Five out of the nine included studies were rated as weak for selection bias as the response rate was low and the sample was not representative of the target audience. All nine studies were rated as strong or moderate for their study design as they all appropriately reported using a random sample or case-control method. All studies were also rated as strong or moderate for confounding variables as they all controlled some, if not most of the differences between participants. For the majority of studies included in this review, it was not possible to assess withdrawal or dropout rates due to studies failing to measure attrition rates or reporting low response rates.

Table 2. Quality assessment results for included studies.

Study	Selection Bias	Study design	Confounders	Blinding	Data Collection Method	Withdrawal and Dropouts	Global Rating
Seneviratne et al, (1998)	Moderate	Strong	Moderate	Weak	Weak	Strong	Weak
Elliott & Long, (2008)	Weak	Moderate	Strong	Strong	Moderate	Weak	Weak
Okumura et al, (2016)	Weak	Moderate	Strong	Moderate	Weak	N/A	Weak
Okumura et al, (2014)	Weak	Moderate	Moderate	Moderate	Weak	N/A	Weak
Beran, (1997)	Moderate	Moderate	Strong	Weak	Weak	N/A	Weak

Study	Selection Bias	Study design	Confounders	Blinding	Data Collection Method	Withdrawal and Dropouts	Global Rating
Vogtle et al, (2007)	Moderate	Strong	Strong	Strong	Moderate	N/A	Strong
Okumura et al, (2015)	Weak	Moderate	Moderate	Weak	Weak	N/A	Weak
Okumura et al, (2013)	Weak	Moderate	Moderate	Weak	Weak	N/A	Weak
Dickey et al, (1993)	Moderate	Strong	Moderate	Strong	Weak	N/A	Moderate

As summarized in Table 1, studies explored perceptions and attitudes of driving with epilepsy. All studies used a quantitative approach by using questionnaires asking either individuals with epilepsy, health professionals and physicians and/or the general public to respond with their opinions on the topic, mostly responding to closed questions. Only one study compared attitudes towards driving with epilepsy between all three participant groups [3]. There were four conducted by one team of researchers [16-19] with a combined sample of 2359. Nearly all studies found that the general public view driving with epilepsy as dangerous and believe people should not be driving with epilepsy despite agreeing that they would drive if they had epilepsy. Two studies examined the perceptions of individuals with epilepsy and how they perceive driving [15, 20] with a total sample of 504 individuals who reported feeling that they should be able to drive to increase their independence. Some of the epilepsy individuals were also found to be driving illegally, disagree with current laws and compliance decreasing as restrictions increased. Two studies with a combined sample of 472 looked specifically at health professionals' perspective of driving with epilepsy [13, 21]. Some doctors felt that driving with epilepsy is dangerous and that restrictions are needed, but rarely asked their individuals if they drive. Doctors reported having a responsibility to report anyone driving against legislation but do not feel responsible for the repercussions this could bring. Studies suggest that the more knowledge a doctor has about epilepsy, the more likely they are to think positively about driving with epilepsy.

3.2. Summary of Findings

1. 9 quantitative studies were included that explored the perceptions and attitudes on driving with epilepsy.
2. Seven studies had a weak global quality assessment rating.
3. There are conflicting perceptions and messages around driving with epilepsy.
4. The more knowledge and understanding about epilepsy, the more positive the feelings are about driving with epilepsy.
5. Epilepsy specialists were more positive about driving with epilepsy than the general practitioners.
6. As driving restrictions increase, compliance decreases.
7. The greater knowledge about epilepsy, the more positive the general public were about epilepsy.
8. Results of this review produced mixed findings, however all studies identified that further information and promotion is necessary on epilepsy and driving.
9. Different attitudes about driving with epilepsy were found within different populations - some felt that

driving with epilepsy is dangerous and restrictions are necessary whilst others felt that restrictions have not helped to increase safety; knowledge and experience was the main contributing factor.

10. Only 9 studies met the inclusion criteria for this review, highlighting not only a shortage of available research in this area, but also the difficulty in drawing any firm conclusions from it.

4. Discussion

This review reveals some clear differences in feelings and attitudes towards the driving behaviour of people with epilepsy. From the individuals' perspective, it is essential for them to continue driving to maintain independence and ability to continue work even though they are aware of the dangers. Health and safety is important to individuals with epilepsy, however individuals still drive illegally and a quarter of drivers with epilepsy reported having had an accident due to a seizure. This could be an important area to look at for increasing perceived susceptibility and for reducing barriers to change. In contrast, views of the general public on driving with epilepsy shift in response to information about epilepsy. Positive responses increase with familiarity and even though media coverage does not significantly affect attitudes towards driving with epilepsy, positive responses do increase following media exposure. Therefore, educating the general public about epilepsy could reduce stigma and negative feelings towards people with epilepsy [11, 14]. There was a marked difference in opinion between family practitioners, who were more likely to oppose a license to individuals with uncontrolled seizures, and neurologists who were more likely to agree to set minimum seizure free period before driving. This points to a need for experienced physicians in the area of epilepsy to have the most input into legislation and to promote education. It is interesting to note that the more exposure people have to epilepsy, the more accepting they are of the condition and this could be an important avenue into reducing the stigma attached to it [11-12].

Unfortunately the lack of studies on patient perceptions markedly limits the conclusions that can be drawn from this review. All studies used questionnaires to collect information from participants about their attitudes towards driving with epilepsy and only two of these studies reported using valid and reliable measures which makes comparing studies difficult. In addition, it was often unclear as to what subgroup of individuals were being referred to in the studies; whether these were attitudes about individuals driving with epilepsy who have achieved seizure control, or those with uncontrolled seizures who continue to drive despite

legislation restricting their driving. The survey design commonly employed also limits the generalizability and quality of the data produced due to low response rates. Moreover, the studies included in this review were carried out in various countries, which have different laws regarding driving after a seizure, this has implications for the interpretation of findings and attitudes of driving with epilepsy need to be considered within this context. Despite limitations of this review, it goes some way in providing tentative answers to some important questions surrounding the attitudes towards people with epilepsy driving motor vehicles:

1. Do health professionals perceive driving with epilepsy as a positive or negative behavior?

Health professionals who work closely with epilepsy individuals are more likely to feel positive about driving with epilepsy than general practitioners who rarely see these individuals. It seems that the more health professionals understand about the condition and how it can affect a person's life, the more likely they are to think positively about driving with epilepsy. This shows how knowledge can affect perceptions about driving with epilepsy and how this can influence recommendations to individuals.

2. Do people without epilepsy perceive driving with epilepsy positively or negatively?

This review posits that the more the public is exposed to epilepsy and understand the topic, the more likely they are to perceive driving with this condition as positive. This is similar to health professionals in that the more experience they have with the condition and the level of personal exposure they have to epilepsy determines their perceptions of driving with epilepsy.

3. What influences individuals with epilepsy to continue to drive against legislation?

Individuals with epilepsy continue to drive against legislation due to wanting to maintain a level of independence, especially if they need to drive to continue working. It was also found that individuals with epilepsy did not agree with current laws on driving with epilepsy and felt that they should be able to drive to remain independent.

4. What recommendations can be made based on this review?

The most important point to take from this review is that compliance decreases as restrictions increase. Therefore, it is plausible to argue that safety over restrictions becomes a shared goal and future work should focus on both the public and professionals to increase education about epilepsy and inform legislation. The importance of increasing knowledge, experience and understanding of epilepsy could help to reduce negativity towards the condition and people driving with it. Both the public and the health professionals showed significant improvements in perceptions, the more experience or knowledge they had with this condition. However, since the methodological quality of studies was low for this small number of reviewed studies, first, more quality research needs to be conducted in this area. Finally, an important prospect for future research would be to identify methods for

reducing the barriers of refraining from illegal driving.

5. Conclusion

This review has highlighted conflicting perceptions and messages around epilepsy and driving behaviour, but the more knowledge and understanding about epilepsy, the more positive the attitudes. Individuals feel that not being able to drive affects their independence. The more driving restrictions increase, the more compliance decreases. Results of this review produced mixed findings, however all studies identified that more information and promotion is needed on the topic of epilepsy and driving. The review examined the conflicting attitudes towards driver safety and legislations amongst drivers with epilepsy and highlights the issues that arise as a result of these conflicting attitudes. Findings pointed to the development of educational tools for the public and healthcare professionals on driving and epilepsy (as well as educating individuals about the risks of driving when having seizures). This review has identified a need for more stringently designed research studies.

Author Statements

Conflicts of Interest

None.

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Ethical Approval

Ethical approval was not required for this study because no new data were collected.

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