Return to driving after a diagnosis of epilepsy: a prospective registry study

Ying Xu,[1,2] Maree L Hackett,[1,2,3] Nick Glozier,[4] Armin Nikpour,[5] Ernest Somerville,[6] Andrew Bleasel,[7] Carol Ireland,[8] Craig S Anderson[1,2,5,9]

1. The George Institute for Global Health, Faculty of Medicine, University of New South Wales, 83-117 Missenden Road, Camperdown NSW 2050, Australia
2. Sydney Medical School, University of Sydney, Sydney, Australia
3. Faculty of Health and Wellbeing, University of Central Lancashire, Preston PR1 2HE, United Kingdom
4. Brain and Mind Centre, University of Sydney, 94 Mallett St, Camperdown NSW 2050, Australia
5. Neurology Department, Royal Prince Alfred Hospital, Sydney Local Area Health District, Camperdown, NSW 2050, Australia
6. Neurology Department, Prince of Wales Clinical School, University of New South Wales, Barker St, Randwick NSW 2031, Australia
7. Neurology Department, Westmead Hospital, Cnr Hawkesbury Road and Darcy Road, Westmead NSW 2145, Australia
8. Epilepsy Action Australia, PO Box 879, Epping NSW 1710, Australia
9. The George Institute for Global Health at Peking University Health Science Centre, Level 18, Tower B, Horizon Tower, No. 6 Zhichun Rd, Haidian District, Beijing, 100088, P.R. China

Correspondence author:
Professor Craig S Anderson
The George Institute for Global Health at Peking University Health Science Center,
Level 18 Tower B, Horizon Tower, No. 6 Zhichun Rd Haidian District, Beijing, 100088
P.R. CHINA
T:+61 2 80524521, +86 10 82800577 ext 557, F:+86 10 8280 0177,
Email: canderson@georgeinstitute.org.cn

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Summary

Purpose: To determine the frequency and predictors of return to driving within one year after a diagnosis of epilepsy.

Method: The Sydney Epilepsy Incidence Study to Measure Illness Consequences (SEISMIC) was a prospective, multicenter, community-wide study of people of all ages with newly diagnosed epilepsy in Sydney, Australia. Demographic, socioeconomic, clinical characteristics and driving status were obtained as soon as possible after baseline registration with a diagnosis of epilepsy. Multivariate logistic regression was used to determine predictors of return to driving at 12-months follow-up.

Results: Among 181 (76%) adult participants (≥18 years) who reported driving before an epilepsy diagnosis, 152 provided information on driving at 12 months of whom 118 (78%) had returned to driving. Driving for reasons of getting to work or place of education (odds ratio [OR] 4.70, 95% confidence intervals [CI] 1.87 to 11.86), no seizure recurrence (OR 5.15, 95% CI 2.07 to 12.82), and being on no or a single antiepileptic drug (OR 4.54, 95% CI 1.45 to 14.22), were associated with return to driving (C statistic 0.79). Over half of participants with recurrent seizures were driving at follow-up.

Conclusion: Early return to driving after a diagnosis of epilepsy is related to work/social imperative and control of seizures, but many people with recurrent seizures continue to drive. Further efforts are required to implement driving restriction policies and to provide transport options for people with epilepsy.

Key Points

- Most (76%) adults drive in the month before their diagnosis of epilepsy, and most (78%) return to driving within the 12 months following their diagnosis.
- Having to drive to/for work or to place of education were key determinants of resuming driving after an epilepsy diagnosis.
- Control of seizures with or without medication was a key predictor of driving within 12 months of diagnosis.

Introduction

People with epilepsy face restrictions from driving or holding a driver's license because of potential harms to themselves and others from loss of awareness and/or motor control from recurrent seizures.[1] As in many other countries, driver licenses in the state of New South Wales, Australia are issued to people who have experienced one or more seizures only if their risk of a collision due to a seizure is considered acceptable, either because of the nature of the seizures or there is a low risk of recurrence. However, as loss of a driver's license can have significant consequences on many aspects of one's life,[2] including influencing medical reviews and adherence to medication,[3] and restricting socialization[4] and leisure activities,[5] it is understandable that people with epilepsy rank driving as their most important concern[6] and are often distressed[7, 8] by driving restrictions. Some will continue to drive against advice,[9] and some will conceal their diagnosis from the licensing authority.[10]

In Australia, people with epilepsy who wish to continue to drive or apply for a driver license are legally obliged to notify the licensing authority of their diagnosis,[1, 11] where upon the licensing authority provides a medical report form for completion by a responsible health professional[1] to certify fitness to drive, according to nationally agreed standards.[1] A seizure-free interval of at least 12 months is required for most people before they are allowed to resume driving. However, shorter periods suffice in situations where there is a low risk of seizure recurrence; for example, 6 month seizure free periods are required after a first seizure, or after patients commence treatment for the first time.[1] In New South Wales, treating doctors are not obliged to report patients who are potentially unfit to drive.[11]

Previous studies of driving in people with epilepsy have had small samples, cross-sectional recruitment, or were undertaken long after a diagnosis of epilepsy was made,

limiting the ability of authors to determine causal relationships.[9, 12] Due to the paucity of prospective research which takes account of pre-morbid driving status, we analyzed data from the adults participants of the Sydney Epilepsy Incidence Study to Measure Illness Consequences (SEISMIC),[13] to determine the frequency and factors predictive of return to driving within one year after a diagnosis of epilepsy.

Methods

The SEISMIC is registered on the Australia New Zealand Clinical Trial Registration database (ANZCTRN12609000059268), and the protocol and main results have been published.[13, 14] In brief, people with a new diagnosis of epilepsy were enrolled over a 6-month pilot phase from July 2008, and over a 3.5-year main phase from June 2010 in Sydney, Australia. The study included people of all ages, but only adult participants (i.e. ≥18 years) are included in these analyses.

Epilepsy was defined as two or more unprovoked seizures, defined according to the International League Against Epilepsy (ILAE) Commission on Epidemiology and Prognosis as “a transient occurrence of signs or symptoms due to abnormal excessive or synchronous neuronal activity in the brain”.

Researcher nurses, who had completed training in the study protocol, interview process, and features of epilepsy, undertook in-person structured interviews with participants within 28 days of their diagnosis or as soon as possible (baseline), and at 4 and 12 months after diagnosis. Each interview included a clinical and an age-specific psychosocial assessments.[13, 14] Thirty-five percent of the participants finished their baseline assessments within 28 days, and participants who had their baseline assessments undertaken beyond the 28-day period, were asked to recall their situation within the first month of diagnosis.

Information was collected on socio-demographic characteristics, clinical pattern of seizures (appendix e-1), use of antiepileptic drugs (AEDs), and other information including use of public and private transport (appendix e-2 and e-3), in the month before diagnosis and in the eight months prior to the 12 month assessment. Driving status was defined by responses to questions outlined in the appendix (e-2 and e-3). If during an interview, driving against recommendation was suspected, the interviewer would not confront the participant, but instead would send a note to the participant's doctor to remind him/her of driving restrictions.

Family function was assessed with the Family Adaptation, Partnership, Growth, Affection and Resolve (APGAR) questionnaire,[15] with responses recorded on a 3-point scale (1 'hardly ever' to 3 'almost always') for 5 questions with higher scores indicating better family function.[15] Alcohol consumption was assessed using the World Health Organization's Alcohol Use Disorders Identification Test (WHO-AUDIT-c),[13, 16] where a total score of ≥5 for males and ≥4 for females[13] indicates 'at risk' consumption. Anxiety and depression were measured using the Hospital Anxiety and Depression Scale (HADS) subscales,[17] which contain 7 items each, answered on a 4-point scale (0 'not at all' to 3 'very often'). A score of ≥8 on corresponding subscales indicating anxiety or depression. Psychosocial disability was measured using the 12-item WHO Disability Assessment Schedule (WHODAS 2.0), with higher scores indicating more psychosocial disability.[18]

In complete-case analyses, Kruskal-Wallis and chi squared tests were used to compare those 'driving' with those 'not driving'. Only variables with an association ($P < 0.2$) with driving in univariate models were considered for inclusion in multivariable models. Where there was high correlation between variables (defined as >0.4), only one was entered into the model. Stepwise removal of non-significant covariates

identified through a likelihood-ratio test was undertaken until all the remaining variables were statistically significant (P <0.05). Data are reported with odds ratios (OR) and 95% confidence intervals (CI). Analyses were undertaken using SAS Enterprise Version 7.1 (SAS institute, Cary, NC).

Results

Among 259 registered adult participants, there were 22 with missing driving status information at baseline and 29 at 12-months, leaving 237 (92%) with driving status available before the diagnosis of epilepsy and 152 with 12-month outcome data (hereafter referred to as the study group, Figure 1). All participants in the study group completed clinical and psychosocial assessments themselves, including with a nominated proxy present in 11 (7%) at baseline and 4 (3%) at 12 months. Compared to those without data on driving status at 12 months, the study group were more likely to be in full- or part-time employment (P = 0.01, hereafter 'in paid employment') and to drive to work or their place of education before an epilepsy diagnosis (P = 0.01), and were less likely to have anxiety or depression at baseline (P = 0.02, Table e-1). Compared with those who had baseline interview conducted within 28 days, more of those who were asked to recall their situation reported they had had seizure frequency more than several times per year within the first month of diagnosis (P = 0.05, Table e-2).

Among the 237 adult participants (median age 40, interquartile range 27 to 58, years; 51% male) with premorbid driving status, 181 (76%) drove a car (Figure 1) at least several times per week (93%). Most (≥80%) considered driving to be 'very or fairly important' and their daily life would be affected 'a lot or to some extent' if they could not drive. Only a minority drove only to work/education (3%) or daily activities (31%), while 92 (51%) drove for both reasons. One-hundred and six (69%) of the 153 people

in paid employment traveled to work by car as drivers or as passengers: 86 as drivers only, 18 as passengers only, and 2 as drivers and passengers.

Participants who drove in the month before their epilepsy diagnosis were older, and more often married or partnered, in paid employment, without major comorbidity, owned their home (with or without a mortgage), had post-secondary education, better family function, higher annual household income (i.e. ≥Aust$100,400), private health insurance, at least two preschool or school aged children, and no family history of epilepsy, compared to those who did not drive (Table e-3). As age was correlated with home ownership (r = 0.4) and presence of comorbidity (r = 0.4), it was not entered into multivariable analyses where the independent predictors of premorbid driving were, being in a relationship (OR 2.32, 95%CI 1.00 to 5.41), better family function (per 1 point increase on family APGAR OR 1.22, 95% CI 1.02 to 1.46), being in paid employment (OR 8.22, 95% CI 3.40 to 19.88), home ownership (OR 2.90, 95% CI 1.19 to 7.04) and no family history of epilepsy (OR 2.89, 95% CI 1.06 to 7.89) (C statistic 0.81, Table e-3). In sensitivity analysis with age instead of home ownership and comorbidity entered into the model, the same variables (i.e. being in a relationship, better family function, paid employment and no family history of epilepsy) were significant.

Of the 152 participants with 12 month outcome data, 118 (78%) reported driving in the preceding 8 months, of whom 106 (90%) indicated that it was ‘very or fairly important’ for them to be able to drive and 85 (72%) said that not being able to drive would affect their daily life (‘a lot or to some extent’). These 118 participants drove less frequently at 12 months compared before their diagnosis: 53% (12 months) versus 69% (before diagnosis) reported driving every day, and 7% versus 3% reported driving less than one day per week, respectively (P <0.0001).

As there was high correlation between driving more frequently and driving to get to work/education (r = 0.5); the latter was used in multivariable analyses where the independent variables for returning to driving were driving to work/education (OR 4.70, 95% CI 1.87 to 11.86), no seizure recurrence (OR 5.15, 95% CI 2.07 to 12.82) and being on one or no AEDs during this time (OR 4.54, 95% CI 1.45 to 14.22; C statistic 0.79, Table 1). We cannot differentiate those who drove to get to work and those who drove to get to place of education. Twenty participants (14%) were both in paid employment and study, 97 (69%) were in employment but not study, 3 (2%) were in study but not employment, and the rest 21 (15%) were in neither.

Thirty two percent of the 152 participants had seizures between 4 and 12 months after their diagnosis, with over half (27/48) having driven at the same time period. One in five participants (27/118) who drove had recurrent seizure(s) but further clinical details are missing.

Discussion

In this large prospective population-based study undertaken in a large city of a high-income country, we found that most adults had a driver's license at the time of diagnosis of epilepsy and driving was strongly related to socio-economic characteristics. Moreover, most people resumed driving within one year after an epilepsy diagnosis and this was related to work or social reasons and lack of recurrent seizures (with or without medication).

We found that 69% of the employed adult participants traveled to work by car as drivers or as passengers, which is similar to the 63% reported by Australia Bureau of Statistics 2011 Census data for New South Wales.[19] Consistent with previous findings, driving was related to being in a relationship or employment, reflecting in part the needs of the

family and importance of living independently.[7, 12, 20-23] Owning accommodation has not been investigated in previous studies, but higher household income has been associated with driving, both reflecting family wealth.[21, 23, 24] Interestingly, people with a family history of epilepsy were less likely to drive in the month before their diagnosis.

Driving to work or a place of education before diagnosis was a strong predictor of driving after diagnosis. Problems with the availability of public transportation have often been cited by physicians[25] and the public[26] as reasons for people with epilepsy disregarding advice about not driving, and re-emphasize the need to consider more accessible public transport or home-based employment opportunities for those with epilepsy.[23] Being seizure-free, or on no or a single AED, may be surrogate markers for mild epilepsy, good disease management, or fewer adverse effects of AEDs making them safe to resume driving,[20, 21, 23, 24] all of which would increase the chance of participants meeting the standard to resuming driving. It is worth noting that although statistical correlation between these two variables (i.e. being seizure-free and <2 AEDs) was not identified, there remains the potential for clinical correlation. We also note that one previous study noted both decreased seizure frequency and fewer AEDs in the final model,[23] whereas other studies identified one of them not associated with driving in univariate analysis.[20, 21, 24, 27]

Seizure etiology (i.e. idiopathic versus cryptogenic and symptomatic) was not associated with driving in the month before the diagnosis of epilepsy, or with returning to driving in the preceding 8 months at 12 months assessment, which is consistent with previous studies,[12, 20, 21] but in discrepancy with one study of people with childhood-onset epilepsy.[28] Lack of comorbidity was associated with driving before the diagnosis and with returning to driving after the diagnosis in univariate but not in the multivariate analysis. This contradicts other studies that report no past/present learning

difficulties,[28] not considering self-disabled,[29] or not receiving disability benefit,[23] as being associated with driving.

Strengths of this study are the inclusion of a large group of adults who were recruited prospectively from multiple health care centers soon after an epilepsy diagnosis and prospectively followed up for an adequate period of time to assess clinical response and readjustment to the disorder and management. However, we acknowledge that the study is limited by selection bias, with those excluded participants more likely to have anxiety or depression, and less likely to have full- or part-time occupation and to drive to work or their places of education before the onset of seizures. This may have led to an overestimation of the frequency of driving, because depression has been associated with the cessation of driving after acute stroke[30, 31] and employment with driving.[7, 12, 20, 22, 23] We acknowledge the possibility of recall bias for 65% of the participants who completed their baseline interviews more than 28 days after the diagnosis. Although our study was large, we acknowledge that the sample sizes used in the models were still too small to provide precise estimates.

Acute symptomatic seizures were not epilepsy, but may later (after 1 week of stroke, anoxic encephalopathy, intracranial surgery, etc.) be diagnosed as epilepsy, if they are not transient/reversible insult, according to the 2014 ILAE operational definition[32] and in present study. Those with one unprovoked seizure with a probability for further seizures occurring over the next 10 years being ≥60%, were defined as having epilepsy in the 2014 definition.[32] In our study, the diagnosis was made after at least two seizures, while driving restrictions apply after even one seizure. It is therefore likely that some patients would already have had a period of non-driving following their first seizure whether epileptic or acute symptomatic and some of them would probably still have not resumed driving in the month before their diagnosis of epilepsy.

Further, we have no information on the recommendations of clinicians and awareness of participants over driving restrictions, nor on the periods of seizure freedom experienced by individual participants before resuming driving. For this reason, we were unable to comment on the fact that over half of those with recurrent seizures returned driving because we do not know whether they had been seizure-free for the required time frame and had been allowed to drive; whether they stopped driving after recurrent seizures; and on how the driving regulations influenced decisions regarding return to driving. There have been only two previous studies, specifically investigating the reasons why people drove in violation of local laws or against medical advice,[12, 29] where a same predictor, being employed, was reported. Finally, our data on driving and clinical course of epilepsy (e.g. seizure onset, frequency and recurrence) was based on self-report and prone to responder bias, particularly as some of the information reported may have exposed illegal actions; although at the beginning of each interview the interviewer indicated that all the information provided would be kept strictly confidential and used only for research.

In summary, our study has shown that return to driving within one year after a diagnosis of epilepsy is related to work and education/social imperative and effective control of seizures. Even so, many people with ongoing seizures continue to drive. Further efforts are required to implement driving restriction policies and provide public transport and flexible employment options for people adjusting to the implications of epilepsy.

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Disclosures of Conflicts of Interest

Ernest Somerville reports personal fees from UCB Pharma and Eisai and speaker fees from SciGen and has acted as a consultant to the National Transport Commission of Australia; and Craig Anderson reports speaker fees and travel re-imbursement from Boehringer Ingelheim and Takeda. None of the named companies had any role in the conduct or reporting of this study. Ying Xu, Maree Hackett, Nick Glozier, Armin Nikpour, Andrew Bleasel, and Carol Ireland report no disclosures.

Ethical Publication Statement

We confirm that we have read the Journal`s position on issues involved in ethical publication and affirm that this report is consistent with those guidelines.

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Table 1 Association between participant characteristics and driving status in the preceding 8 months before 12 months assessment

Variable (at baseline unless specified)	Driving status		P value	AOR (95%CI)
	Driving (n = 118)	Not driving (n = 34)		
Demographic and socioeconomic factors				
Age, years	41 (28, 56)	43 (32, 55)	0.70	
Male	65 (55)	16 (47)	0.41	
Married/partnered[a]	67/116 (58)	21/31 (68)	0.31	
Post-secondary education	64 (54)	15 (44)	0.30	
Risk drinking level (≥5 for men, ≥4 for women on WHO-AUDIT)	36 (31)	11 (32)	0.84	
Family function (APGAR), n	15 (13, 15), 116	15 (14, 15), 34	0.91	
Full/part time paid employment before diagnosis	96/113 (85)	23/30 (77)	0.28	
Full/part time student	23/117 (20)	5/33 (15)	0.56	
Annual household income ≥Aust$100,400	53/110 (48)	18/33 (55)	0.52	
Encountered economic hardship[b]	31 (26)	14 (41)	0.09	
Private health insurance	77 (65)	19 (56)	0.32	
Own accommodation with/without mortgage	65/117 (56)	15/34 (44)	0.24	
≥2 preschool or school aged children in the household	20/105 (19)	7/32 (22)	0.73	
Drive to work/education	77 (65)	11 (32)	<0.001	4.70 (1.87 to 11.86)
Drive frequency (≥3 or 4 days per week)	95/117 (81)	23/33 (70)	0.15	
Other licensed driver in household[e]	99/116 (85)	23/26 (88)	0.68	
Clinical factors				
No comorbidity[c]	88 (75)	17 (50)	0.006	
Anxiety or depression (≥8 on HADS anxiety/depression subscales)	33/115 (29)	12/32 (38)	0.34	
Psychosocial disability (WHO-DAS), n	14 (13, 16), 118	15 (13, 20), 32	0.28	
Epilepsy-related characteristics				
Symptomatic[d]	44 (37)	11 (32)	0.60	
Seizure frequency more than several times per year	32/105 (30)	13/29 (45)	0.15	
No seizure occurrence in preceding 8 months[e]	91 (77)	13 (38)	<0.001	5.15 (2.07 to 12.82)
<2 AEDs[e]	110 (93)	23 (68)	<0.001	4.54 (1.45 to 14.22)
No family history of epilepsy	88/107 (82)	27/32 (84)	0.78	
Stigma[f]	26 (22)	11 (32)	0.22	
				C statistic 0.79

Data are number (percentage) or median (interquartile range).

AOR denotes adjusted odds ratio, CI confidence interval, WHO-AUDIT World Health Organization Alcohol Use Disorders Identification Test alcohol consumption part, Family APGAR Family Adaptation, Partnership, Growth, Affection and Resolve questionnaire, HADS Hospital Anxiety and Depression Scale.

P values are for the comparisons of drivers with non-drivers. Kruskal-Wallis and Chi squared tests used for continuous and categorical variables, respectively. If there were missing values, the actual denominators were presented.

[a]Versus no current partner (i.e. never married, widowed, divorced or separated)

[b]Either an instance of a household`s inability to make a necessary household payment (i.e. gas, electricity or telephone bills, heat or cool home, mortgage or rent payments, etc.) or the demonstration of dissaving behavior (i.e. borrowing or use of savings, sell assets, borrow money, etc.)

[c]Includes self-reported cardiovascular, respiratory, ophthalmology, otorhinolaryngology, gastrointestinal, hepatic, renal, genito-urinary, musculoskeletal and endocrine-metabolic diseases, but not including neurological (e.g. epilepsy) and psychiatric/behavioral conditions

[d]Symptomatic epilepsy due to encephalitis or meningitis, head injury, stroke or brain operation, versus idiopathic epilepsy

[e]Variables collected at 12 months, reflecting the situation in the preceding 8 months

[f]As a result of epilepsy, the participants think that other people are uncomfortable, treat them differently, or prefer to avoid them

Figure 1 Flow of adult participants` driving status in the SEISMIC