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The impacts of a driving ban: A socio-legal empirical analysis of the everyday experiences of people living with epilepsy in Finland

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Abstract

This qualitative study explores the impact of driving ban legislation on individuals with epilepsy in Finland, focusing on how these limitations affect their everyday life. We do this by empirically analysing material from qualitative interviews, examining the experiences of individuals who have had a driving ban imposed on them. The findings reveal that driving is perceived as a crucial aspect of autonomy and identity, with significant implications for daily life and social participation. The study highlights the rigidity of current legislation regarding driving bans, which often fails to consider individual circumstances, leading to feelings of frustration and unequal

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opportunities. Recommendations include improving communication about legal guidelines, providing tailored support and enhancing access to alternative transportation services. This research contributes to the understanding of how driving restrictions intersect with broader socio-legal barriers, advocating for more inclusive policies that better support the mobility rights of individuals living with epilepsy.

Key words

Epilepsy, driving ban, law and society, socio-legal studies, impacts of laws, epilepsy and law, access to justice

Resumen

Este estudio cualitativo analiza el impacto de la legislación sobre la prohibición de conducir en las personas con epilepsia en Finlandia, centrándose en cómo estas limitaciones afectan a su vida cotidiana. Para ello, analizamos empíricamente el material obtenido de entrevistas cualitativas, examinando las experiencias de personas a las que se les ha impuesto una prohibición de conducir. Los resultados revelan que conducir se percibe como un aspecto crucial de la autonomía y la identidad, con importantes implicaciones para la vida cotidiana y la participación social. El estudio pone de relieve la rigidez de la legislación vigente en materia de prohibiciones de conducir, que a menudo no tiene en cuenta las circunstancias individuales, lo que genera sentimientos de frustración y desigualdad de oportunidades. Entre las recomendaciones figuran mejorar la comunicación sobre las directrices legales, proporcionar apoyo personalizado y mejorar el acceso a servicios de transporte alternativos. Esta investigación contribuye a comprender cómo las restricciones a la conducción se entrecruzan con barreras sociojurídicas más amplias, abogando por políticas más inclusivas que respalden mejor los derechos de movilidad de las personas que viven con epilepsia.

Palabras clave

Epilepsia, prohibición de conducir, derecho y sociedad, estudios sociojurídicos, repercusiones de la legislación, epilepsia y derecho, acceso a la justicia

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1. Introduction

There are over 70 million people living with epilepsy worldwide, and approximately 60 000 people with epilepsy in Finland; more than one sixth of them have a severe form of epilepsy (Kälviäinen *et al.* 2016, 8–10, Vera-González 2022). Epilepsy can be well controlled with medication. Approximately 70 percent of people with epilepsy live without epileptic seizures in Western countries, such as Finland. Epileptic seizures are a danger to traffic safety, which is why driving licenses for people with uncontrolled epilepsy are restricted worldwide (Willems *et al.* 2019). However, the obligation or right of doctors to report a patient's epilepsy to driving authorities varies across countries. There are also differences with restrictions in regulation. Different jurisdictions require different seizure-free periods for different types of epilepsy (Beran 2008, 646). Also, not all report their epilepsy to authorities (Krumholz *et al.* 2016).

European studies show that 73% of people with epilepsy hold driver's licenses, compared to 94% of the healthy adult population (Möller *et al.* 2023). Finland was not included in the study, and therefore we do not have an estimate of the numbers in Finland. The national authority, the Finnish Transport and Communications Agency (Traficom) do not maintain a direct, public registry tracking driver's licenses by specific conditions or illnesses.

Previous research on the driving rights of people with epilepsy has examined factors associated with people's employment situation and driving licenses (Tedrus *et al.* 2010); patients driving without permission (Willems *et al*. 2019); the risks of epilepsy in traffic (Bener *et al.* 1996, Black 2001, Nishida *et al.* 2020); the knowledge, attitudes and practices of neurologists working with driving restrictions (Beran *et al.* 2007, Caruana *et al.* 2018); the knowledge and attitudes of driving license applicants with epilepsy (Anselme *et al.* 2022); the impacts of driving status regulation (Hafner *et al.* 2014); the narratives of driving with neurological conditions (Stepney *et al.* 2018); and differences in driving regulation and guidelines across countries (Winston and Jaiser 2012, Möller *et al.* 2023, Mulcahy *et al*. 2025).

Driving is regarded as an integral part of modern life, and an increasing number of people have driven throughout their adult life. Losing the ability to drive can cause a variety of problems in work life, education and social relationships (Krumholz *et al.* 2016). Studies have shown that the loss of driving increases the risk of social isolation, poor quality of life and even depression (Savoie *et al.* 2024). These negative consequences have been connected to the loss of independence and freedom (Bauer *et al.* 2003, Adler and Rottunda 2006) and reduced out-of-home activity (Marottoli *et al.* 2000), as well as being connected to abrupt and involuntary transitions in life caused by the driving cessation (Musselwhite and Shergold 2013). Interestingly, the ability to drive has been perceived as a sign of youthfulness, and the loss of it is seen as a transition to old age (Siren and Hakamies-Blomqvist 2005, Musselwhite and Shergold 2012). However, research focusing on younger people's experiences related to the loss of driving has been limited and scarce among people with epilepsy.

In our current project, the research team has examined access to justice and the implementation of rights for people with epilepsy in Finnish society (see Issakainen *et al.* 2024, Järvinen *et al.* 2026). The study investigates access to justice through the lens of legal problems faced by individuals with epilepsy and the barriers to accessing their

rights. The loss of driving license due to epilepsy is just one of the prominent themes that emerged in the interviews. This issue is frequently noted in previous research on the experiences of individuals with epilepsy and is arguably significant (e.g. Beran 2008), as it represents how a chronic illness can affect people's everyday lives, sense of self, as well as a sense of being treated justly and equally. Drawing from the theoretical framework of access to justice, we will utilize the concepts of lived law and legal consciousness to explore how everyday legal problems are experienced, recognized, and interpreted by individuals (Erlich 1936/2019; Ewick and Silbey 1998). The fundamental premise here is that people's experiences and awareness of their rights and the functioning of the legal system are distinct from the law as a formal system (Obstbaum *et al.* 2025). When examining legal regulations, our focus will be on Finnish legislation.

We begin the article by systemising relevant legal norms concerning epilepsy and driving internationally and nationally. After describing the setting, we move on to describing the theoretical framework through which the effects of law in everyday life can be interpreted. We then move on to describe the material and methods of the study, after which the analysis of how the legal framework impacts on the lives of people living with epilepsy will be presented. We will be asking the questions: (1) How does a driving ban affect the lives of people with epilepsy? and (2) What challenges do people with epilepsy and professionals working with them perceive in the implementation of the relevant legislation? We do this by analysing empirical data, consisting of interviews with 26 Finnish people living with epilepsy and 12 Finnish professionals working in healthcare or nongovernmental organisations.

2. The right to drive for people with epilepsy — the legal framework

2.1. Driving bans in different countries

One key factor affecting the lives of people with epilepsy is the fact that people with epilepsy are usually banned from driving motor vehicles. The reason for the driving ban is road safety as epileptic seizures while driving can lead to road accidents (see Taylor *et al.* 1996, Black 2001, Naik *et al.* 2015). In many Western countries, doctors are obliged to inform the authorities responsible for driving licenses about patients' epilepsy (see, e.g. Beran *et al.* 2008, 646–647). Doctors have an obligation to notify the authorities in Finland and several other European countries, such as Latvia, Lithuania, Norway and Sweden. In Denmark, there is an obligation to notify the authorities if the illness or condition poses a direct risk to other road users and the driver does not stop driving voluntarily (HE 146/2017).

Internationally, there has been much debate on this topic, including debate from legal viewpoints. In the United States, for example, as early as the 1950s, in various states people with epilepsy were required to have a seizure-free period of between one and three years to obtain a driving license. Some states also required an uninterrupted period without medication. This resulted in a debate as to whether it was fair to deny the right to drive to people with epilepsy in the interests of safety (Perr 1958, 29–296). Doctors in different countries have also objected to having to report epilepsy to the authorities. They have argued that this can damage the medical relationship and lead to "doctor shopping" or patients concealing their seizures. Thus, if patients fear the risk of losing

their driving license, they may avoid going to the doctor at the risk of losing treatment and services (Hoffman Snyder 2005).

2.2. The EU directive on driving licenses

The EU Driving License Directive (2006/126/EC) sets the minimum standards for physical and mental fitness for driving a power-driven vehicle in Annex III. Drivers are classified in two groups according to the vehicles they drive: Group 1 includes the drivers of mopeds, motorcycles, tractors, passenger cars and vans, and Group 2 includes the drivers of lorries, buses and trucks. Generally, a driving license shall not be issued or renewed for applicants with a serious neurological disorder without an authorised medical opinion about driving health (Annex III, Section 11). In addition, there are specific provisions concerning people with epilepsy.

Epileptic seizures are considered a significant road safety risk. A person is considered to have epilepsy if they have had two or more epileptic seizures that were less than five years apart. Provoked epileptic seizures have an identifiable, avoidable cause. After any first seizure or loss of consciousness, driving must stop and a specialist report is required (Annex III, Section 12). Provisions are different, depending on seizure type (such as a provoked epileptic seizure, a first unprovoked seizure, other forms of loss of consciousness or diagnosed epilepsy).

In Group 1, licenses are not granted automatically to people with epilepsy. Generally, a five-year seizure-free period is required, but shorter periods may apply depending on the seizure type and medical assessment. A license may be issued after a provoked epileptic seizure if it is unlikely to recur while driving. After a first or single unprovoked seizure, a driving license may be issued after six months without another seizure or even sooner if the prognosis is good. People with diagnosed epilepsy may drive after one year without seizures. People who have seizures that only occur during sleep or those without an influence on consciousness or ability to act may also be declared fit to drive (Annex III, Sections 12.1–12.9). In all, the provision leaves discretionary power to national legislators and authorities, as well as to doctors.

In Group 2, stricter criteria apply. Applicants must be seizure free without anti-epileptic medication for the required period. In addition, a neurological assessment, including EEG, must confirm normal brain function. Driving may be permitted after a provoked epileptic seizure if the event is unlikely to recur. After a first unprovoked seizure, at least a five-year seizure-free period without medication is required, though national authorities may allow an earlier return to driving. For diagnosed epilepsy, a ten-year seizure-free period without anti-epileptic medication is generally needed, again, with limited national discretion (Annex III, Sections 12.10–12.14).

2.3. Finnish legislation on driving

In Finland, driving rights and driving bans are regulated by the Driving License Act (386/2011) which implements the above-mentioned EU directive. The act follows the directive's two-group classification of vehicles (§ 4). A license may only be issued if the applicant meets the health requirements (§ 12.1), and neither Group 1 nor Group 2 drivers may have a disease that substantially impairs driving ability (§ 17.1[3], § 18.1[4]). The act refers directly to Annex III of the directive, which lists relevant conditions,

including epilepsy. For Group 1, seizures while sleeping are assessed in the same manner as seizures that occur while awake (§ 17.2).

Although the police are legally responsible for monitoring driving health, doctors have a central role in ensuring driving health. The police may require a medical certificate if there is doubt about fitness to drive (§ 20.1), and doctors are legally obliged to notify the police if they find that a patient no longer meets the health requirements for a driving license (§ 21.1). Before making such a notification to the police, the patient must be informed (§ 21.3). If the health requirements are no longer met, the police impose a driving ban (§ 64.2), typically based on the doctor's statement. To support consistent practice, the Finnish Transport and Communications Agency has issued guidelines for doctors on driving health assessment (Traficom 2021).

For Group 1 drivers, when a person has had an epileptic seizure, doctors usually impose a temporary driving ban of three months if no underlying brain disease is detected and the EEG (electroencephalogram) does not suggest epilepsy. If there is a predisposition to recurrent seizures, the ban is 12 months. A single recurrence within three years leads to another 12-month ban. Seizures caused by medically supervised medication can reduce a 12-month ban to a three-month ban. Epilepsy is not a permanent barrier to driving, but 12 seizure-free months are generally required before a favourable medical certificate can be issued (Traficom 2021, 29).

For drivers in Group 2, an initial or isolated seizure results in a five-year driving ban. The health requirements for driving are only met if the driver has no seizures and is not using anti-epileptic medication during this period. A neurologist must assess the prognosis for epilepsy and the length of the driving ban. For diagnosed epilepsy, doctors cannot issue a favourable statement. Health requirements for driving are met only after 10 seizure-free years without medication (Traficom 2021, 29–30).

In sum, although the directive leaves room for interpretation, Finnish regulation is comparatively strict. Seizure type has little effect, and in practice, a person with epilepsy must be seizure free for one year to drive Group 1 vehicles. Obtaining or retaining Group 2 licences is extremely difficult for people with epilepsy. Because a valid medical certificate is required, the doctor assess the condition and with that determines the right to drive.

A recent amendment (113/2025, § 22.2) to the Health Care Act (1326/2010) removed the obligation of public health services to provide the medical certificates required by the Driving License Act. People with epilepsy must now obtain these certificates by private providers, creating financial and regional inequalities due to higher costs and uneven service availability.

2.4. Legislation on mobility support services

A person with epilepsy may be eligible for mobility support services, but eligibility is not automatic and requires an assessment based on the applicable legislation. Mobility support can be provided in various forms, including transport services, personal assistance, accompaniment, group transport or the reimbursement of reasonable transportation costs, such as taxi fares (Disability Services Act 675/2023, § 29; Social Welfare Act 1301/2014, § 23).

Under the Disability Services Act (§§ 28–31), individuals with disabilities have a statutory right to receive the mobility support necessary for work, study and essential daily travel. Eligibility requires meeting the act's scope criteria: the functional limitation must be long-term or permanent, or the person must have another illnesses or disability causing equivalent difficulties (§ 2). According to the act, a person is entitled to mobility support if they have "particular difficulties in transportation and are and are unable to independently use public transport or only able to independently use it with unreasonably great difficulty" (§ 28). This formulation leaves room for interpretation by the authorities applying the law.

Under the Social Welfare Act (§ 23), mobility support may be granted to individuals unable to use public transport due to functional limitations. When a person with epilepsy does not fall in the scope of the Disability Services Act, mobility support can still be provided under the Social Welfare Act. Primary means for providing this support include public, demand-responsive or service transport (§ 23.1), but if a person "is unable to use public transport independently due to illness, disability or another comparable cause", other arrangements may also be made (§§ 23.2–3).

In practice, people with epilepsy may experience inconsistent access to mobility support, particularly when the impact of their condition on functional capacity is interpreted narrowly. Much depends on the policies and decision-making practices of individual well-being services counties, which may lead to regional differences in how mobility support is granted. These potential disparities cannot be fully analysed based on our data.

3. Theoretical framework

As mentioned in the introduction, this study is situated within the "living law" research tradition (Erlich 1936/2019) or the "law in action" approach (Pound 1910). The theoretical basis of this study is grounded in a socio-legal access to justice framework (Cappelletti and Garth 1978, Obstbaum *et al.* 2025). We aim to examine how the law is lived, experienced, and interpreted by individuals, while simultaneously looking at whether people feel they have the abilities or resources to enforce their rights (Cappelletti and Garth 1978). This approach encompasses notions of how people experience justice and equality, as well as distributive justice (Rawls 1968). We will apply these concepts in relation to the legal framework outlined earlier, aiming to illustrate how this legislation impacts individuals' lives in practice and how they make sense of their situation.

The focus is thus on subjective experiences and perceptions of regulatory norms and how they are interpreted, and at times contested, by people (Ewick and Silbey 1998). How the laws regarding driving and mobility support are interpreted and implemented in practice shapes the everyday experiences of people living with epilepsy (e.g. Beran 2008, Beran *et al.* 2020, Järvinen *et al*. 2026). Additionally, the cessation of driving can significantly affect everyday life, bring about limitations, and influence one's sense of self and autonomy. What is evident is that driving for many represents freedom and normalcy, and serves as a symbol for adult life (Stepney *et al.* 2018).

With this notion in mind, we will combine this socio-legal approach with insights from sociological theorizing of chronic illness and its social consequences, particularly the notion of chronic illness as a biographical rupture (Bury 1982). The illness and what is

means in terms of legal consequences — in this case losing the driver's license — can be seen as a rather profound change in adult life. In other words, it is through the law as it is implemented that the consequences of one's illness materialise in everyday life. Moreover, in line with Bury (1982), we see uncertainty as a key aspect of this rupture, particularly pertinent as the seizures can be unpredictable. For instance, the law stipulates that losing the license following a seizure lasts for one year. However, in practice, this is less straightforward, as it cannot be predicted if or when individuals will have another seizure. Thus, how the law is experienced is not straightforward, even if it might appear so on paper- for laypeople the interpretation and implementation can be obscure.

4. Methods and data

The research project has received a supportive statement based on an ethical pre-assessment by the research ethical committee of the University of Eastern Finland (statement 17/2023).

Semi-structured, thematic individual interviews with people with epilepsy (n = 26) were conducted between May 2023 and December 2023 all over in Finland. The request for interview participants was distributed through the Finnish Epilepsy Association (through its internet page, magazine and events). All people who expressed their interest to participate in the study were included in the sample. The aim of the study was to determine legal needs and problems, and the realisation of the rights of people with epilepsy. To gain a comprehensive picture of how these issues are understood and how they manifest in everyday life we chose to include both people living with epilepsy, as well as professionals that work with these issues such as doctors, nurses and people working in the Finnish Epilepsy Association.

The interviews with people with epilepsy lasted from 45 minutes to two hours. The interviews were mainly conducted at the interviewees' homes, whereas some were conducted at the university premises, or public places. Before the interviews, the participants received an information sheet containing details about the study. All the interviewees signed an informed consent to participate in the study. Six of the interviewees were men and twenty were women. On average, they were about 40 years old (mean age: 41; median age: 38). The youngest of the interviewees was 16 years old and the oldest one was 70 years old. The severity of epilepsy varied between the individuals. Some remained under treatment with medication and had no seizures. Others had severe epilepsy and had frequent seizures. Some were working or studying, and some were retired or unemployed.

At the beginning of the interview, the interviewee was allowed to speak freely about their life with epilepsy. The pre-planned questions focused on potential everyday problems and challenges faced by individuals with epilepsy, available or lacking support or help, and perceived well-being. Thus, the interviews did not only touch upon the problems related to driving, but rather explored various aspects of everyday life, such as work, access to services, social relations, as well as experiences of discrimination (see Appendix). Yet, losing one's driving license was one of the key issues that the interviewees mentioned (see also Järvinen *et al*. 2026).

In addition, two types of interview data were also collected from professionals who encounter people with epilepsy in their work. The first dataset consists of a focus group discussion involving four organization workers from the Finnish Epilepsy Association, a non-profit organisation offering support and information services for people and families living with epilepsy. The second data set is made up of individual interviews with six healthcare professionals, four of whom were doctors specializing in epilepsy and two were nurses from three central hospitals. Also, these participants an information sheet containing details about the study and signed an informed consent to participate in the study. The interview framework mirrored the structure aimed at those living with epilepsy, emphasizing legal needs, issues, and the realization of rights.

The recorded interviews were transcribed verbatim. The analysis started off with a thorough reading and thematization of the material into different themes- including for example social relationships, experiences of discrimination, access to services and support, and driving and mobility. The focus of this article was driving and mobility and thus we did a more fine-grained coding related to driving utilising Atlas.ti software. The codes were partly predetermined based on previous research and theory, whereas some emerged from the data. In practice, we began with a data-driven coding, followed by a more theory-driven approach, looking for recurring patterns, themes or concepts within the data. Lastly, we considered the significance of these themes, focusing on how the legal framework forms the conditions within which people with epilepsy navigate their everyday lives and adapt to the possible limitations.

5. Results

The main findings were divided into three themes, firstly focusing on various social consequences and limitations to everyday life, which included areas such as work, living arrangements, inadequate services and social relationships. The second theme focuses on the experiential aspect of a sense of self and being in control of one's life, which often seemed to be affected by the driving ban. Lastly, the third theme focused on a recurring problem that professionals and people living with epilepsy identified, namely, that the implementation and interpretation of the legislation was oftentimes not that simple. The results are presented below with extracts from the interviews to illustrate the findings. The extracts were translated from Finnish to English and anonymised to protect the participants.

5.1. Limitations to everyday life

First, we elaborate on limitations to everyday, normal life that the cessation of driving or not obtaining a license might bring about. The onset of illness or receiving a diagnosis can disrupt many activities that are typically taken for granted, such as hobbies and commuting to work. What we show is that the driving ban affects various fields of everyday life and forces people with epilepsy to adapt to sometimes challenging situations. As we show below, organising everyday life may require complicated arrangements.

<u>Work</u>

A key requirement in the current labour market is access to mobility (Stepney *et al*. 2018). Being mobile is closely linked to employment opportunities, as well as to both economic

and social capital (Farber and Paez 2009). A substantial body of literature highlights the advantages of car ownership and the economic gains associated with it (Cervero *et al.* 2002). A recurring theme emerging from the interviews was the impact of illness on working life, particularly the limitations it imposed.

In Finland the long distances and the situation and expectations of the labour market, with decreasing job opportunities, particularly outside of densely populated areas, often force people to commute long distances. Many participants expressed concerns about their inability to commute to work, and some had to make difficult arrangements to reach their workplaces. In addition, some of the respondents were entrepreneurs who would have needed to be able to drive to manage their business. This is exemplified in the extract below, where the participant explains their commuting arrangements and how their mobility is dependent on other people's schedules:

> Quite often, when I have gone to [Place A], I have left home at half past six with my husband. Then my husband has taken me to my friend, [X], who lives in [Place B] and works in [Place A]. I have gone there. Then I have set up the coffee maker there and gone to sleep on the sofa until she wakes up, at around 08:00. Then we drink coffee and I go with her to [Place A]. Then I come back, either with [X] or with [Friend B] (...). It depends on what kind of day they have. Then, if I should go to [Place C] or [Place D] to meet a client, there's practically no way I can get there. If I go to the office [Place A], I go with my husband or I go by bike, depending on what kind of day I'm having. (Woman, 36)

The professionals also discussed concerns linked to working life, stressing that, in some cases, the ban can force people to find new career paths. This highlights its broader implications on the identity and self-image of the person (discussed more in the next section). Those identifying strongly with their line of work were seen as particularly vulnerable, as one doctor elaborated:

> Disability or rehabilitation solutions can be offered if you have been a professional driver and epilepsy prevents you from working […] Then, of course, statements are written and the search for a new profession begins [...] These are sometimes, or often, very difficult for people to understand. When your identity has been that of a truck driver or something similar, it takes a tremendous amount of time to go through the process of establishing a new identity, and people get stuck in that process. [...] It's not just about the driving ban but also about everything related to it. Pilots. Terrible situations. If your whole life has been built around being able to drive a motor vehicle like that, it leads to a collapse. (General practitioner)

In sum, this theme focuses on the limitations to working life brought about by the driving ban in terms of having to rethink commuting to work and having to adjust to the fact that not all occupational possibilities are open to people with epilepsy after its diagnosis.

Living arrangements and services

What can be read from the accounts is that the restrictions to driving also impact on the residential choices of the participants living with epilepsy, as is explained by one participant:

> To some, it may seem like a minor issue, but from my perspective, a person with epilepsy who does not have a driver's license is automatically forced to move to a city, preferably one with a university hospital. (Man, 39)

Both the people with epilepsy and the professionals expressed their concerns for those living in the countryside and their sense of having fewer opportunities than those living in urban areas. In the quote below, the person discusses the limitations that living in the countryside brought about, which resulted in the choice to move to the city:

> When I wanted to try studying or working after high school, there was hardly any public transport there [in the countryside] (...). Then I thought that I needed to get a better grip on life, somewhere where there was more life around me. So, I moved to [City X]. (Woman, 38)

The key issue regarding living arrangements is the eligibility for transport services. As mentioned in the legal framework section, transport services can be attained based on the Disability Services Act or the Social Welfare Act. In most cases, having temporarily lost one's license did not entitle people to these services, and even if it did, both professionals and people with epilepsy recognised that the services could often be insufficient, unsuitable or not meet their needs:

> I really enjoy going to flea markets, for example. The only thing I do is pay the assistant for petrol money. That's how it works. But then there's (...) that one assistance service where they require me to have a car for the assistant to drive. I say that this principle is ridiculous. Why would someone without a driver's license have a car? Besides, my spouse uses the car in our household. Just think about it for a moment. (Woman, 52)

The above quote and the one below, illustrate how the decisions made by service providers did not consider variation in individual situations, and thus, their decisions can result in situations that seem unreasonable for people with epilepsy. What the participants seemed to call out for was tailored support services that acknowledge the uniqueness of every situation. Not receiving any support for mobility felt unfair when they compared their situation with those of people with other kinds of limitations. For example, the interviewee below felt that they were not disabled enough to get the support they needed. She discusses not being eligible for transport services because she has no physical limitations in terms of mobility and thus could use public transport, without acknowledging other aspects, such as the availability of public transport in her area. This exemplifies the implementation of the legislation in practice; as a rule, there is a possibility to grant services based on an evaluation of the individual's needs, but in practice, the transport services are often limited to those who have physical limitations to their mobility:

> That transportation assistance is peculiar, and I'm so fixated on it because it annoys me. The most ridiculous thing is that I'm not disabled enough for it because I can use public [transportation]. What f***ing public transport? (…) The person who originally rejected my application [for transportation assistance] knows very well that there is no public transport [in her locality]. (Woman, 36)

Not getting the needed services not only had effects on the person with the diagnosis, but it also more broadly had effects on the person's family life:

> Of course, it is a problem if you have epilepsy and your home is somewhere out in the woods. That is the problem we face. Transport services under the Disability Services

> Act are not available if you have been banned from driving for less than a year. In my opinion, that is an injustice. If you have a family, you have no way of going out to take care of yourself, and when you're out with your children, you're always dependent on someone else. (Finnish Epilepsy Association professional)

Moreover, what becomes evident is that being able to drive is not only linked to work but also to the ability to take part in leisure activities or to maintain social relations:

> But not having a driver's license (...). The girls went out somewhere in the evening, but I couldn't go because I live so far away and summertime affects all transportation [in Finland, buses run less frequently in rural areas during the summer]. (Woman, 48)

In sum, this main theme discussed the limitations to mobility and its social consequences, particularly in the context of work, living arrangements and access to support services. What it shows is that not being able to drive impacts on various fields of life, both in practical terms and in terms of identity and autonomy. In practice, not having the right to drive means that they are not able to freely choose where to live. Moreover, in terms of living arrangements, what is evident is that those living in rural areas, and particularly those living alone without informal support networks (friends, family, neighbours), have less opportunities compared with those living in cities. Another practical implication of the driving ban is that some need to reconsider their occupation or at least make amendments in their work. These restrictions thus mean that they have limited occupational choices compared with those who do not live with the condition.

Furthermore, a sense of inequality also stems from the perceived lack of support services. In practice this often means transport services. Often, epilepsy is not seen as a sufficient reason to get these services as it is interpreted as not restricting normal life to a considerable extent or because a ban is temporary. Often, how profoundly the illness and cessation of driving might affect the organising and managing of everyday life or one's sense of autonomy are not considered. In the interviews, it seems that the people with epilepsy are not considered ill or disabled enough to gain support services, even though they feel it limits their life, sometimes quite considerably.

5.2. A sense of self and having control of one's life

In this section we illuminate the impacts on the sense of self and one's sense of being in control of one's life, focusing on the experiential aspect of not driving, in other words, on how the interviewees give meaning to and make sense of their non-driving life. Here it becomes evident that the driving ban serves as a critical event that forces individuals to re-examine their self-concept and their relationship with the social world (Bury 1982, Stepney *et al.* 2018)

<u>Autonomy/independence</u>

Previous research has shown that driving is perceived as an integral aspect of an individual's personal history and a part of everyday life, representing both individual freedom and opportunity (Stepney *et al.* 2018). This is also a theme that is exemplified in our data:

> When you got your driver's license at the age of 18 and have been an independent person and travelled a lot, [losing your license] limits your sense of freedom in a certain way. (Woman, 59)

The participants expressed that losing their driver's license diminished their sense of autonomy. This change was usually initiated, overseen or monitored by others, including authorities and loved ones, which led to feelings of discomfort due to being watched or scrutinised (see Stepney *et al.* 2018). In the extract below, the participant explains how her children keep an eye on her:

> 'Well, you can't take our car since you don't have a driver's license. You won't be having any accidents with it.' They [her adult children] live in [Place X], in the middle of the woods, but there are neighbours nearby. However, they do take me there as a kind of a 'dog sitter.' I feel that they don't think I'm completely handicapped, that I can still take on some responsibility. Or do they have a surveillance camera? I've always wondered where it is here. (Woman, 59)

The issue of being under scrutiny was also recognised by the professionals. A doctor shared their observation that driving is often considered a part of "normal" adult life and that non-driving was sometimes met with preconceptions. Thus, people with epilepsy needed to explain their situation to others:

> And yes, I know of situations where (...) you can't say that you have epilepsy and that's why you can't drive because then your friends and people around you start wondering if you're banned [from driving] because of drunk driving. That kind of gossip starts. One person said that people had started talking about how her husband wouldn't let her drive anymore. (General practitioner)

Moreover, there was a sense of discomfort at being dependent on others, maybe echoing the will to maintain a sense of autonomy or responding to the expectation that adult individuals can manage their everyday lives independently. In the extract below, the participant exemplifies this by saying how she refuses her mother's help, not wanting to be a burden:

> My retired mother said that you should call if you need anything. That she can take me here or there, but I don't think it's right. My retired mother shouldn't have to drive me to work. (Woman, 36)

Identity

Driving can be very important for people's identities. Being able to drive can bring about a sense of normality (see also Stepney *et al.* 2018) and is seen as a profound part of adult life. One of the interviewed doctors identified the driving ban as the most pressing issue for people when receiving the diagnosis:

> In fact, nothing else is a problem, only the driving ban is a problem. Not only because of the practical implications for women and especially for men. It's possibly a kind of identity issue. It's somehow ingrained in us that it's a fundamental right and a kind of measure of whether you're a normal person. (General practitioner)

For some, driving and its restriction can seem like mundane things that only last for a fixed period of time, but for others, the wait and the fear that they will have another seizure — which in practice means another year of not driving — is something that has rather profound consequences on their lives. This was not always recognised by practitioners, as exemplified by the extract below where the participant talks about their

outrage when they felt the doctor saw their condition as a minor ailment, not acknowledging how, in reality, the resulting alterations had big and profound effects on her life:

> During my last visit to the neurologist, I asked how accurately they record those [seizure-free periods] and when I will have been seizure free for a year. Unfortunately, it will be January, and I had thought I would get my card back in December. Now, when we start lowering the dosage of the medication, goddamn it, if I have another seizure, should I just keep quiet? (…) Then there's the bitterness too. In December, I was given two weeks of sick leave. I remember the doctor saying that I wouldn't even notice I had epilepsy if I was on the right medication. I thought, 'OK'. If I saw that woman [the doctor], I could tell her something. (Woman, 59)

In terms of the identity management in the extract below, the person living with epilepsy claims to have skills and abilities linked to driving, even though they cannot drive themselves. This outlook might have served as a way of managing identity struggles; even though they could not do things that are normatively expected from "normal adulthood", they did possess similar, or better, navigational skills than their spouse who has a license:

> My spouse sometimes asks me from behind the wheel where they should be going and which lane they should be in. Even though I don't have a driver's license, I tell him to get out of that lane and turn there because that's the best and fastest way to get there. It's as if I were behind the wheel myself because I know the route so well from riding with my friends. (Woman, 52)

Moreover, the professionals in particular discussed identity management, drawing on gendered understandings linked to driving, emphasising that they consider driving to be of importance to men in particular:

> Then, maybe cars are more [important] to men (...) a bit stereotypically? Of course, there are different people, and there is diversity and variation in that. But in professional matters, [it] may be emphasised (...). If there is a young man who has already served in the military, does not own a car and is planning to work in an office job, then I am always [sighs out in relief]. (General practitioner)

<u>Adapting and adjusting</u>

It was mostly the professionals working with people living with epilepsy that discussed how to best promote adaptation and adjustment to the diagnosis. What makes this task hard is that there is no certainty of how the condition will develop or manifest in the future. Thus, adaptation becomes a life-long process as, on one hand, the state of the condition might change and, on the other hand, life situations and aspirations evolve:

> It's probably the unexpected nature of the illness or not necessarily knowing how it will behave in the future. There is the initial shock, but then, other shocks can occur throughout life because the illness can also change slightly or one can be in good seizure control and then, after five years, the situation can change. This [requires] adaptation in many ways and in different things, depending on the person. (Finnish Epilepsy Association professional)

One medical professional discussed how long-term adjustment could be best supported. They recognised that the situations the patients are in are multiple and, thus, the ways to support them should also be tailored according to their needs. For example, they felt

it is not always in the best interest of the patient to give them (possibly) false hope that life would go back to the way it was after the one-year driving ban as they could not guarantee they would regain their license. Rather they hoped that adjustment and support for a new life without driving would also be considered:

> If you have been diagnosed with epilepsy, it does not necessarily mean that you will remain seizure free for a year, for example; it could be anything . In my opinion, the best thing to do when epilepsy is diagnosed is to start thinking seriously about the options. It may be better, if at all possible, not to live there [far from public transportation] in the future. (...) If you have clearly developed epilepsy, then your life changes (...). I feel that, in any case, a lot of resources in the social and health care sector are being put into things that could be better targeted, and resources should not be put into supporting this idea that life should continue as before. (General practitioner)

In sum, this main theme discussed the implications of the driving ban in relation to the sense of self and how the professionals promote adjusting to the changes. It seems that a sudden cessation of driving is particularly difficult to accept, whereas those that have never been eligible to drive might be better adjusted to life with a driving limitation. The professionals promoted supporting adaptation to the new, non-driving life as a process, acknowledging that individual situations vary and that the patient's future with the condition cannot be completely foreseeable. For people living with epilepsy, the changes in everyday life were sometimes felt as profound, altering the very core of one's self-image, whereas sometimes the changes were felt to be a divergence from their "normal" life, a life to which they would soon be able to return. In some cases, the possibility of a new seizure, resulting in a renewed one-year driving ban, threatened this return.

5.3. Implementing the law in practice

In this section we explore how the legislation is interpreted in practice by people living with epilepsy, as well as by professionals working with these issues. It shows that, in practice, the law is not straightforward and causes some considerations and uncertainties, both for professionals and for people with epilepsy.

<u>Interpreting the legislation</u>

As mentioned earlier, the main reason for a driving ban is road safety (Taylor *et al.* 1996, Black 2001, Naik *et al.* 2015). This is also considered as the most pressing argument for the ban by both professionals and people with epilepsy. However, the people living with epilepsy balanced arguments for safety, on one hand, and for everyday practicality, on the other. For practitioners, the instructions and legislation regarding the ban were experienced as helpful. They could distance themselves from the decision to issue a driving ban as another authority issued it (see also Liddle *et al.* 2014). Emotional outbursts, showing how important driving is to people, were not uncommon when receiving the decision, and the professionals found these situations difficult. However, they could now support their argument by referring to the legislation:

> Well, everyone has to give it [a driver's license] up. That's what I always say. It does not matter if you are 15 or 100 years old, the rules are like this. It is a safety issue. It is probably the one thing, when getting the diagnosis, that people get most upset about. This is of course understandable. (Nurse)

In the interviews, a call for better recognition of the complexity and variation in individual situations was visible. As mentioned in the legal framework, the directive allows for interpretation and discretion. This is something that people with epilepsy in particular would welcome; treating all people the same is not always seen as the most suitable solution. It seems that, for laypeople living with epilepsy, it was sometimes hard to understand the legislation and its consequences. While the legislation can seem quite straightforward on paper, for the person with the diagnosis, the situation can seem unclear and cause uncertainty. This is something that the professionals often deal with in their work:

> [Losing] the license is an issue that really is discussed as there is no clear-cut answer as to what the situation [of regaining the license] is. It also evokes a lot of emotions and thoughts in these people. (Finnish Epilepsy Association professional)

Due to the difficulties in interpreting the legislation, the ban can seem unreasonable, and one of the interviewees said it felt like a punishment. What they call out for is more individualised and flexible solutions, hoping that the implementation of the legislation would acknowledge the variability of people's situations and conditions. This is exemplified in the extract below where the participant compares her situation with that of her brother who had suffered a stroke:

> I told the doctor that this was completely unfair. If someone seeks help, you punish them with this [driving ban]. I've been driving for 20 years (...), I've never had a traffic violation, and now they're taking my license away. (…) I had one epileptic seizure, and there was a causality. Stress and medication [caused it], and then I got a one-year [driving ban]. Now my older brother, who is almost 50, had a stroke. He had some kind of blockage here [in his brain]. He was half paralysed, but then they managed to dissolve it [the blockage] quickly. His [driver's license] was revoked for 3–6 months. What the hell? (Woman, 38)

Thus, what further intensifies the sense of injustice is the comparison with people with other (seemingly) similar neurological conditions or limitations that might jeopardise road safety. It seems that they feel that the preconceptions or even stigma associated with epileptic seizures might put them in an unequal position compared with others. The comparison with people with other conditions was also identified by one of the doctors as something that complicates their work; it seems hard for the patients to grasp why they are not allowed to drive for a year when others only get a shorter ban. Thus, the implementation of the law in practice can sometimes seem unwarranted for the patients.

Monitoring and evaluating fitness to drive

Monitoring the ban presents itself as difficult for the participants, and the responsibilities seem to not always be that clear. As mentioned in the legal framework, the authority that is responsible for the monitoring the issue is the police, but in practice, general practitioners and other physicians recognise that they play an important role. Doctors must inform the police if they find that the applicant's or driving license holder's state of health has deteriorated or when they no longer meet the health requirements for a driving license. Some doctors found it a burden having to report such cases to the authorities. As shown in previous research, they saw that they had a responsibility on which they could not follow through. They argued that there is always a risk for "doctor

shopping" or patients concealing their seizures (Hoffmann Snyder 2005). Concealing seizures is also identified in our data as an issue that makes monitoring hard in practice.

People conceal their seizures , not only due to practical reasons, but also due to emotional reasons; driving is such an important part of their lives (for those that have lost their license in adulthood — maybe this does not apply so much for people who never were eligible to drive) that it feels unfair and unreasonable to be restricted from driving. In some cases, the uncertainty of the duration of the ban and the feeling of unreasonableness led them to figure out ways how they could circumvent it. Even a temporarily issued ban can have significant consequences for their everyday lives, and that can result in dismissal of the doctor's statement (Patomella *et al.* 2009, Liddle *et al*. 2014) or to situations where people considered concealing their seizures to regain their license after the ban:

> Now they're threatening that if I have another seizure, my driver's license will be revoked. I've given instructions at home and at work that if I have a seizure, don't fucking call an ambulance. I can't take this anymore. I think it's wrong to punish people for [seizures]. There should be some kind of concession. (Woman, 38)

Also, the professionals recognised situations where people try to conceal their condition or figure out ways of evading the ban. Also, in some cases, the patients might not recognise their seizures and thus are not able to report them. One of the interviewed doctors stated that the follow up of the ban is "surrendered to divine will".

Furthermore, one of the professionals discussed the possibility of going around the ban via private healthcare. Even though they did note that this was a more pressing issue before shared online patient record systems, they did recognise that the current system is still not impregnable. Moreover, as mentioned in the legal framework-section, having to resort to private healthcare might put people living in more remote areas or people that do not have the means to pay for a private doctor in an unequal position compared with others as they do not have (easy) access to these private services:[8]

> So, it [imposing a driving ban] should be equal for everyone, but unfortunately, we have so-called yes men among our doctors. This happens especially in private practices, where people come with money and pay for it, so you get some of those opinions there. It's easier to ignore things you know about there. Kanta [the patient database] now exists. Now it's a little more difficult [to ignore things], but especially in the past, if you didn't have all the information, you just asked the patient and then wrote something down. (General practitioner)

People living with epilepsy expressed that they needed to be aware of their rights, as well as have the capacities to claim these rights. One of the interviewees felt that they had to be insistent to get their ability to drive reassessed as the epilepsy nurse did not advance the matter:

> They [the epilepsy nurse] won't send a message about this to the neurologist. I [said]: 'It's your job to send a message to the neurologist.' I now have permission to get my driver's license back (...). She said: ´No, no, no. There has to be something else in life. You have to find something else [in life] besides that driver's license.' Then I had to call the head nurse to say: 'This can't be true. I'm not getting anywhere with my epilepsy

[8] After the interviews were conducted, the legislation changed and public health care no longer gives statements about fitness to drive.

> nurse. I've called three times now, and the nurse still hasn't sent a message to my neurologist about this driver's license issue.' (Woman, 34)

In sum, the ban is considered an issue of safety, and the doctors recognise their role in evaluating the fitness to drive. The legislation and guidelines are considered helpful in this task. On the other hand, some of the doctors found that following the ban is less straightforward in practice as there is variation between practitioners and thus there are ways of trying to evade the ban. For people with epilepsy, the legislation could, on one hand, seem unclear and vague, and on the other hand, the interpretation of the law in practice seemed quite rigid. This resulted in a sense of being unreasonably or unfairly treated. As already mentioned in earlier sections, comparing one's situation with that of people with other kinds of conditions further exacerbated this sense of unfairness.

6. Discussion

The findings of this study illuminate the entangled ways in which a driving ban affects the lives of individuals living with epilepsy. The results of this study are in line with previous research (e.g. Krumholz *et al.* 2016, Stepney *et al*. 2018) highlighting that driving is not merely a mode of transportation, it is deeply intertwined with various aspects of life, including work, living arrangements and family dynamics. The social barriers faced by people living with epilepsy are multifaceted and interrelated, necessitating a broad understanding of their implications. For instance, the inability to drive can severely limit housing choices as individuals may be unable to commute to work or access essential services.

Moreover, the study complements previous research that has shown that driving is often perceived as a symbol of autonomy and normalcy (see also Stepney *et al.* 2018). This perception can create a sense of loss for those who are banned from driving, affecting their identity and self-esteem. This aligns with Bury's (1982) theoretisation of chronic illness as a biographical rupture, where the driving ban serves as a critical event that forces individuals to re-examine their self and their relationship with the social world. As previous research has shown, the unexpectedness of the cessation of driving can trigger strong reactions (see, e.g. Patomella *et al.* 2009). Based on this, we suggest that there can be differences between the experiences of those who have never held a driver's license and those who have lost it unexpectedly. The former group is already adapted to not driving, while the latter group often struggles with the abrupt change and its associated challenges (Musselwhite and Shergold 2013, Savoie *et al.* 2021).

In line with Bury (1982) we see that the rigidity of legislation surrounding driving health for individuals with epilepsy adds another layer of complexity to their experiences. The uncertainty of chronic illness, and how it complicates interpretation and implementation of the legislation can lead to feelings of frustration among people trying to navigate the implications of their diagnosis. Applying the legal consciousness perspective has enabled us to deepen the understanding of how individuals make sense of the law in their daily lives. In other words, whether they accept the consequences, use the law as a resource (for example when claiming their rights to be reassessed for eligibility to drive), or in some cases resist the law through concealment of seizures or "doctor shopping" (Ewick and Silbey 1998). It has also enabled us to show how the law on paper is not always the same as living law with a chronic illness.

7. Conclusions

The article concludes that driving is a crucial aspect of adult life, and a sudden cessation of driving can have profound effects on individuals' lives, impacting their sense of autonomy, identity, and well-being. Losing a driving license often imposes significant restrictions on social participation, everyday arrangements, and choices regarding residence and employment. Moreover, the interpretation and implementation of the law in practice play a critical role in people's experiences of equal and fair treatment. Furthermore, the study shows how uniform application of a formally equal rule can produce materially unequal effects, for example when assessing eligibility of mobility services in rural areas. What the article further notes is that the recent transfer of the issuance of medical certificates to the private sector can be seen as a potential factor in enhancing structural inequalities by worsening economic and regional disparities in the future.

Several recommendations emerge from the findings. First, it is vital to recognize the multifaceted ways in which the loss of driving rights affects individuals living with epilepsy. Secondly, clear communication regarding legal guidelines and available support services is essential, as uncertainty can exacerbate stress for those affected. Early interventions focusing on adaptation and acceptance following a diagnosis can facilitate a smoother transition for individuals facing mobility restrictions. Beyond this, specific support structures such as psychosocial support protocols, or specialised mobility counselling when the ban is imposed could help people adjust to their new situation (Savoie *et al.* 2024). Additionally, enhancing access to mobility support services for people with epilepsy can help alleviate some of the burdens associated with transportation challenges.

While this study offers valuable insights into the subjective experiences of individuals with epilepsy, it also has its limitations. The findings are based on a limited self-selected sample size, with primarily women respondents. Moreover, the results primarily reflect the individual experiences rather than providing a comprehensive overview of how driving legislation affects people's lives or how it is implemented across different well-being service counties. Future research could benefit from a broader dataset that includes a more diverse range of experiences and could examine systemic discrepancies in transportation service decisions across various regions. Moreover, a more balanced gender distribution could provide a deeper understanding of how the driving ban may impact social roles and identity differently between genders.

In summary, while driving may seem like a rather mundane and a singular issue, it seems that, for people with epilepsy, it is one of the main lenses through which they make sense of the limitations brought about by the illness. By acknowledging the complexities of the everyday barriers they encounter, we can work out more supportive measures for individuals living with epilepsy.

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Appendix. Interview framework

The focus of the research is on the access to rights and the realization of rights for individuals living with epilepsy. The interviewees will first be asked background information such as age, place of residence, when the illness began, and what type of epilepsy they have. The interviews will be semi-structured thematic interviews. The themes of the interview are as follows:

1. **Everyday Life and Legal Issues:** When were you diagnosed with epilepsy? Can you describe everyday life living with epilepsy? Have you faced issues in your daily life (for example, related to social and healthcare services, education, employment, housing, or transportation services)? If so, what kind of issues? Have you found solutions to these problems, and how? Do you feel you can live life in your own terms and can you influence decisions about your own life?
2. **Prejudice and Discrimination:** Have you encountered prejudice or negative attitudes related to epilepsy? If so, what kind, and how have these prejudices affected your life? Do you have experience of discrimination because of your epilepsy? If you have faced prejudice/discrimination, do you feel that it has impacted your opportunities in various areas of life and your self-image, etc.?
3. **Quality of Life and Meaningfulness:** What issues do you feel are diminishing your quality of life? What factors enhance or maintain your quality of life? What do you enjoy? What gives your life meaning?
4. **Support in Everyday Life:** Do you feel you receive enough support in your daily life? Who do you receive support from? Is there anything where you need more support? What kind of close relationships do you have, and what is their significance?
5. **The Position of individuals with Epilepsy in Society:** What is the status of individuals living with epilepsy in society, and how could this status be improved?
6. **Finally:** Is there anything else you would like to address regarding this topic? How did you experience participating in the interview?