

Законска регулатива кај пациентите со епилепсија - 5 годишна студија

Никодијевик Д¹, Банева Д.Н¹, Кедева К², Петровска Ц.Д.¹, Чавдар К, Стојковска Ф³

¹ Универзитетска Клиника за Неврологија, Медицински Факултет Скопје,

² Американ Колеџ Скопје,

³ Министерство за Надворешни работи на Македонија

стракт

Зовед: И покрај напредокот во дијагностиката и третманот на епилепсиите, пациентите се сеуште експонирани на стигма, стигма и дискриминација, не само од етички и етички аспект, но и во рамките на здравствениот систем. Имено и покрај актот на парламентаризацијата за епилепсија усвоена на Европскиот Парламент, која е со цел да се подобри квалитетот на животот на пациентите со епилепсија, многу земји се соочуваат со проблеми во законската регулатива и права на овие пациенти, како што се тие во доменот на запослување, социјален статус, едукација, здравствено осигурување. Целта на нашата студија е да се проучат законските проблеми кај како и социјалните пречки, со кои оваа категорија пациенти се соочува, преку евалуација на пациентите кои се пријавиле на клиниката последните 5 години.

Методи: Во рамките на 5 годишна проследивна, отворена студија, беа евалуирани 150 пациенти (150 мажи, 131 жени), претходно дијагностицирани како епилепсија, кои пријавија на Невролошката Клиника во Скопје. Примарните параметри кои ги истражуваме беа проблемите во работното место, едукацијата, фамилијарните и социјални проблеми, додека секундарни параметри беа едукација на криминални акциденти, додека на возачка дозвола, социјална помош, проблеми во спортот и бременоста.

Резултати: Од вкупно иследените пациенти во студијата 58 (20.6%) пријавија проблеми во работното место, 38 поради зачестени напади и ризик на работното место, додека 20 беа одбиени од работа поради постоечка дијагноза. 124 пациенти (44.1%) пријавија социјални проблеми, (кај 28 беа регистрирани поради непознавање за состојбата од пријатели, 2 пациенти од колегите, 4 пријавија проблеми во фамилијата и разводни постапки). 12 пациенти во добивање на возачка дозвола, 3.5% од пациентите, од кои кај 20 беше

пријавено зачестеност на напади, а 18 имаа забрана за тешки товарни возила. Кај 48 (17%) од пациентите се регистрираа проблеми со бременоста и пороѓајот, од кои 42 има зачестена фреквенција на напади поради промена на антиепилептичната терапија, 6 пријавија абортуси или тератогени ефекти. Вкупно 12 пациенти имаа проблеми со законските прописи во главном поврзани со напади во тек на сообраќајна незгода, а ниеден не пријави криминогено или агресивно однесување. Кај еден пациент беше регистриран проблем со спортските активности (повторување на нападите после балетска претстава.) Ниеден од пациентите немаше социјална помош.

Заклучок: Студијата потврди дека пациентите со епилепсија се соочуваат со социјални проблеми и нерешени законски регулативи особено во рамките на фамилијарното право, едукацијата, вработувањето, како и добивање на возачка дозвола. Затоа е потребно да се направат и некои реформи во здравствениот систем, како и да се зајакне улогата на Лигата за Епилепсии на РМ во отварање и разрешување на проблемите на пациентите со епилепсија, имплементирање адекватна легислатива да се заштитат правата на овие пациенти, како и да се подобри правните законски регулативи за одбрана на пациентите. Декларацијата за Епилепсии во Европскиот парламент како и правната регулатива на ИЛАЕ, Фондацијата за Епилепсија на Америка и Англија, се добра рамка за пример на подобрување на квалитетот на животот на овие пациенти. Со оглед на легалните и етички импликации кои се појавија во студијата и секојдневната клиничка пракса со овие пациенти, неопходноста и приоритетот се јасни за да се предложат промени во законската регулатива на правата на овие пациенти, кои ќе ги следат Европската Директива (Декларација), и практично да се спроведат во земјата.

Клучни зборови: законска регулатива, епилепсија, отворена студија

Legal issues of patients with epilepsy - a 5 year study

Nikodijevic D.¹, Baneva N.¹, Kedeva K.², Petrovska C.D.¹, Cavdar K., Stojkowska F.³

¹ University Clinic of Neurology, Medical University Skopje, Macedonia;

² University American College, Skopje,

³ Ministry of Foreign Affairs of the Republic of Macedonia

Abstract

Background and purpose: Despite the advancements in the diagnosis and treatment of epilepsy, patients remain exposed to stigma, prejudice and discrimination, not only from a moral and ethical point of view but nonetheless in the eyes of the legal system. Namely, regardless of the enactment of the written declaration on epilepsy by the European Parliament, which had been intended to improve the quality of life of patients with epilepsy, many countries still face problems with the legal rights of these patients, such as in the domain of employment, social status, education and healthcare. The aim of our study is to investigate the relevant legal issues and social problems that this group of patients face by examining the ones admitted to our clinic in the past 5 years.

Methods: In a 5 year prospective, open-labeled study, 281 patients were assessed (150 of which male, and 131 female) previously diagnosed as having epilepsy and admitted to the Clinic of Neurology in Skopje, Macedonia. The primary endpoints were evaluation of employment problems, education, family problems and social discrimination, whereas secondary endpoints assessed were criminal justice, driver licensing, insurance and disability benefits, sports and pregnancy matters.

Results: Overall 58 (20,6%) patients said to have experienced problems with employment and at the working place, 38 of which were due to frequent seizures and risk on the working place, and 20 had problems to get employed with their diagnosis. 124 patients (44,1%) reported to have had social problems (28 claimed to have been rejected by their friends and social circles for their condition, 92 lacked acceptance from colleagues at work, and 4 experienced family problems and divorce). Difficulties with obtaining a driver's license, or it's renewal was reported by 38 (13,5%) patients, 20 out of which had worsening of the seizure frequency and 18 were rejected a driv-

ing permit for heavy vehicles. 48 patients (17%) were pregnant woman out of whom 42 had worsened seizure frequency due to change of AED treatment, and 6 had birth death or birth defects. Overall 12 patients reported to have had criminal law problems (4,2%) mostly connected with a seizure attack during a car accident, and none had violent behavior or evidence of any criminal conduct. One patient had a sport/activity related problem (whilst attending a ballet group) with recurrence of seizures after the performance. None of our patients had state insurance disability benefits.

Conclusion: Our study confirmed that patients with epilepsy experience vast social problems and legal challenges in particularly in the domains of family life, education, employment and other social aspects such as driver's license concerns. It is therefore necessary to make reforms in the national health care system and empower the role of the National Epilepsy Foundation in resolving and putting forward the social concerns of these patients, as well as implementing appropriate legislation to protect the rights of people with epilepsy, and at the same time improve the legal defense programs in resolving criminal law issues. The Epilepsy Declaration of the European Parliament and the rules and regulations of the International League Against Epilepsy, as well as the work by the foundations in the US and UK are a good framework for addressing the problem closer and improving the quality of life of these patients. Having in mind the legal and ethical implications that arise in these cases, together with the legal requirement of the country to align with the European aquil, it is inevitable to put forward a proposal for a law or regulation that would take into account the European Directive, and put it in practice in our country.

Key Words: legal issues, epilepsy, open-label study

Introduction

Over the past decades great progress has been made in the diagnosis and treatment of patients with epilepsy. That being said, it is even evidenced in the wording of the written declaration on epilepsy by the European Parliament¹, that up to 70% of people with epilepsy could be seizure free with appropriate treatment. However despite these advances, still a lot of fear, stigma and discrimination remain pertinent in society on this topic. In many countries, laws enacted to affect and assist the lives of people with epilepsy fail to adequately protect these people and in some countries there is a complete absence of legislation regarding those rights. The research conducted in more than 50 states by the ILAE/IBE/WHO within the framework of the global campaign against epilepsy, analyzing epilepsy related legislation, revealed that many laws affecting people with epilepsy, failed to meet today's criteria for fulfilling the international human rights standards. In America there is the Epilepsy Foundation which can provide people with legal guidance, or a provide referral to an attorney to help and assist with legal cases involving discrimination based on epilepsy.

For example one of the biggest problems affecting these people is the issue of employment discrimination. Some colleges can refuse to make academic admission, or qualified workers may be denied job opportunities due to stereotyped views about risk of having seizure at the working place. Thus, for instance in the US there is a particular act dealing with this issue, the so called ADA (American Disability Act) and it's amendments (ADAAA) by which state employers are not allowed to question job applicants whether they have had certain disabilities as long as they meet the criteria for performing the jobs. But they might be allowed to ask for some medical documentation as long as there is equal treatment of all applicants. Also there is the Rehabilitation Act that allows applicants who are discriminated to file a complaint to the Federal Equal Employment Opportunity Commission (EEOC) Further to this the Commission will investigate the case and decide if there has been violation of the law (the ADA), and whether a legal action is possible.

Another common problem that is frequently reported among these patients is social accep-

tance at school or at home. The Disability Education Act (DEA) proclaims that every child with a disability is entitled to receive a free, appropriate public education in the least restrictive setting. Students with epilepsy may not need special education, but certain assistance to allow them to fully participate in the school might at times be required. So elementary schools, and high schools and colleges are required to provide such services under the Act. This act also covers giving anti seizure medication under the federal law funding of public schools scheme, and allows for extra time if needed to complete tests as well for the students concerned.

Sometimes the case is that a parent with epilepsy faces family law disputes, and should work closely with an attorney, physician and social worker to solve the problem. For instance in a divorce proceeding the parent with epilepsy may be denied custody of his child, but case law states that epilepsy by itself should not be the sole basis for denial of custody, only may be considered as a legitimate factor in determining the child's best interest.

Yet another legal issue that could arise with people suffering from epilepsy is criminal conduct and problems with the law, such as arrests for trespass, shoplifting, and aggressive or violent behavior. Not rarely are there cases where car accidents happen thereby unintentionally leading to severe cases with victims, even death cases as a result of this condition as well. In fact their behavior was involuntary and was solely a result of seizure or postictal confusion. So some Epilepsy Foundation have conducted training of police officers about recognizing and properly treating these patients with due care. Hence, if a patient gets arrested for seizure related behavior, he can contact his lawyer or doctor to assist him and the charges will be dropped. Also he can put charges against the officer for harmful behavior.

Another very common issue that patients with epilepsy face in their daily lives is the one of obtaining and renewing their driver's license.² The law covering this problem varies in different states. Some need to have medical report for several months' seizure free periods, and others ask for 1 or more years seizure free periods. Each state has some kind of hearing and review procedure if it denies or revokes a license because of a medical condition. Usually a medical report, state law and Epilepsy Foundation of the state recommendations are of help in these cases. Fac-

1 European Parliament, Written declaration on epilepsy, 18.01.2016; Retrieved from: <http://www.europarl.europa.eu/sides/getDoc.do?type=WDECL&reference=P8-DCL-2016-0001&format=PDF&language=EN>

2 http://ec.europa.eu/transport/road_safety/pdf/behavior/epilepsy_and_driving_in_europe_final_report_v2_en.pdf

tors in determining whether the license should be renewed are having a seizure free period, rare attacks and nocturnal attacks.

Finally, a common question posed by many patients with epilepsy is can the patient exercise or play sports? It is evidenced that in fact moderate sports activities and regular exercise may improve seizure control and physical, mental and emotional well-being. It is just important to take appropriate care and avoid sport related injuries that can increase the risk for seizures. Exercise is rarely a trigger for seizure activity.

The European written Declaration on Epilepsy has been of great help in improvement the quality of life of the people with epilepsy. The auspices and advocacy of the ILAE/ IBE in collaboration with Epilepsy Advocacy Europe as a joint task force have enacted it.³ Written Declarations are a good tool used by the European Parliament to lunch a debate on subjects that come within the European Union remit. The Declaration was signed by 459 countries, the highest number of any actual Declaration signed. It points to all members to take initiatives to ensure equal quality of life for epileptic patients, including education, employment, transport and public health care.

Methods

Two hundred-eighty one patients were enrolled in a 5-year open-label prospective study, in patients that admitted to our Neurology Clinic. A collaborative retrospective work on the topic was done by a neurologist from the University Clinics of Neurology in Skopje, Macedonia (from the National Epilepsy League in Macedonia) and lawyers from the Ministry of Foreign Affairs of the Republic of Macedonia and the University American College Skopje. The primary endpoints evaluated were employment problems, education, family and social issues in our patients with epilepsy. Secondary parameters that had been evaluated were criminal justice, driver's licensing, insurance and disability benefits, sports and pregnancy matters.

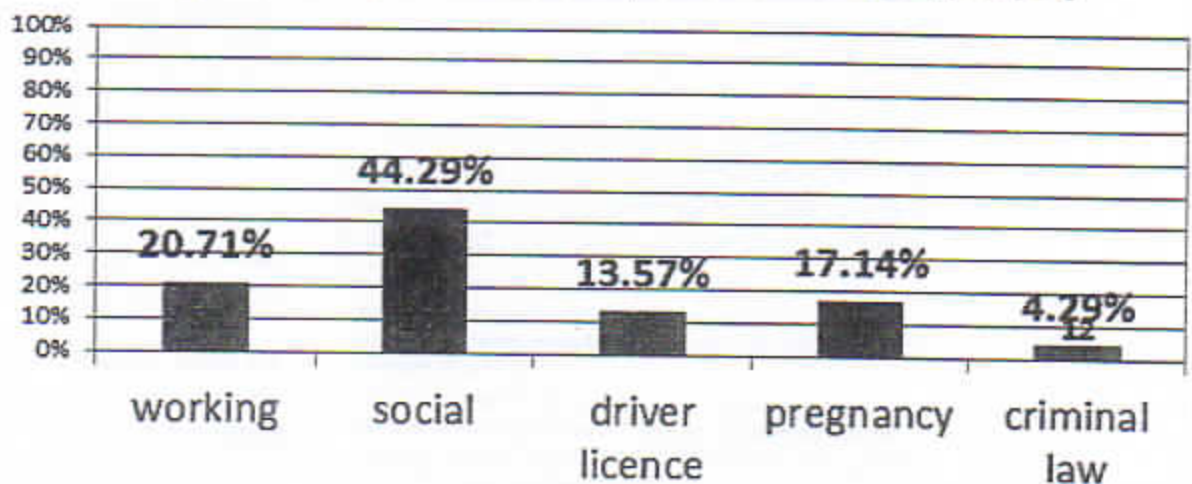
Results

Overall 58 (20,6%) patients said to have experienced problems with employment and at the working place, 38 of which were due to frequent seizures and risk on the working place, and 20 had problems to get employed with their diagnosis. 124 patients (44,1%) reported to have

Legal issue problems in patients with epilepsy

working	social	driver licence	pregnancy	criminal law	TOTAL
20.71%	44.29%	13.57%	17.14%	4.29%	100%
58	124	38	48	12	280

Legal issue problems in patients with epilepsy



³ Baulac, M., de Boer, H., Elger, C., Glynn, M., Kälviäinen, R., Little, A., Ryvlin, P. (2015). Epilepsy priorities in Europe: A report of the ILAE-IBE epilepsy advocacy Europe task force. *Epilepsia*, 56(11), 1687-1695. doi:10.1111/epi.13201

social problems (28 claimed to have been rejected by their friends and social circles for their condition, 92 lacked acceptance from colleagues at work, and 4 experienced family problems and divorce). Difficulties with obtaining a driver's license, or it's renewal was reported by 38 (13,5%) patients, 20 out of which had worsening of the seizure frequency and 18 were rejected a driving permit for heavy vehicles. 48 patients (17%) were pregnant woman out of whom 42 had worsened seizure frequency due to change of AED treatment, and 6 had birth death or birth defects. Overall 12 patients reported to have had criminal law problems (4,2%) mostly connected with a seizure attack during a car accident, and none had violent behavior or evidence of any criminal conduct. One patient had a sport/activity related problem (whilst attending a ballet group) with recurrence of seizures after the performance. None of our patients had state insurance disability benefits. (Table 1)

So our study finally showed that most of the patients with epilepsy that were admitted to our clinic had faced unresolved social problems, and were victims of employment discrimination.

Discussion

Although most legal and medical experts, and nonetheless those working in the field of medical ethics that rights of patients from a fragile group such as those with epilepsy should be aimed at protecting them and having a positive effect on the law in providing the help and easing their life in society. That is in fact the very purpose of the enactment of the European declaration on epilepsy, which in it's wording says: "take initiatives to encourage Member States to ensure equal quality of life, including in education, employment, transport and public healthcare, for people with epilepsy, e.g. by stimulating the exchange of best practice;"⁴ The more important purpose of the EU declaration on epilepsy would be to call on member states to introduce appropriate legislation in order to protect the rights of these individuals.

Despite all of the aforementioned, most national legal systems, including our own, are designed in a manner to place patients in a position to "seek approval" for themselves and prove themselves in front of authorities, such as in the cases with obtaining work permit, or performing their daily jobs, seeking school or college admis-

sion or obtaining a driver's license, they even go so far in some legislations as to purport the right to pregnancy. The fact is that legal systems cause disparities between the right to privacy and professional privilege⁵ thereby causing confusion between the legal and ethical recommendations that are made to doctors in the field. An example for that would be the Italian law on driving licenses that was intended to implement a European directive, but included a provision for mandatory notification by the physician if a driver is epileptic. This mandatory notification was deemed to cause invasion of the right to confidentiality and also interceded with the law on patient information, because it would potentially lead to patient's refusing to seek treatment and obtain the relevant information for their health with such a rigid setting. Thus in this case the Italian Board of Physicians has sought an urgent revision on this law, with the recommendation of optional self reporting by epileptics as a preferred method.⁶ It is pertinent in medical law and ethics to balance the interest of the individual versus that of the community, and thus it is important to draft regulations and recommendations to that effect that will bare in mind the basic human rights of patients that could be perceived as a potential, implicit risk to the community.

Neurologists have agreed that automatism reactions are very rare.⁷ It is however concluded that automatic reactions of violent behavior could occur during or after an epileptic episode but patients are in most cases unaware of their reactions and thus must be treated outside the offenders and detention scheme. In the past they were dealt with in English law as 'insane automatism' and there were reactions that proposed changes in this law in order to protect this group from unlawful detention.⁸

Further to this it has been concluded that ictal violence is very rare and when it does occur it takes the form of a resistive violence due to physical restraint of the patients and their confusion

5 Beran, R. (1997). Professional privilege, driving and epilepsy, the doctor's responsibility. *Epilepsy research*, 26(3), 415-21. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/9127722>

6 Pinchi, V., Norelli, G., & Bartolini, V. (2013). Ethical implications of Italian legislation on "epilepsy and driving." *Journal of medical ethics*, 40(8), 552-7. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/23900293>

7 Treiman, D. (1986). Epilepsy and violence: Medical and legal issues. *Epilepsia*, 27, . Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/3720715/>

8 Paul, G., & Lange, K. (1992). Epilepsy and criminal law. *Medicine, science, and the law*, 32(2), 160-6. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/1614301>

caused after the seizure. There are a number of factors that need to be proved prior to determining that a specific violent act was a result of an epileptic seizure and these are: determining that a patient is epileptic by a competent neurologist, the presence of such automatisms should be documented in the case history, and in a closed circuit TV-EEG procedure, and "the aggressive act should be characteristic of the patient's habitual seizures"⁹, and finally a clinical judgment has to be made by the neurologist that the violent act was in fact part of a seizure.

Despite these rare cases, mostly epileptics are of no threat to society what so every and every effort should be made to include them in society. These people should be seen more as human beings in need of greater protection from the law and the physicians, they are still perceived in society as a threat. Thus various research groups and task forces across Europe and internationally, unite in order to purport the rights of people with epilepsy. Hence, The European Forum on Epilepsy Research (ERF 2013), held in Dublin Ireland,¹⁰ was designed to appraise epilepsy research priorities in Europe through consultation with clinical and basic scientists, as well as representatives of legal organizations and health care providers. The main goals were to improve the lives of persons with epilepsy by influencing the political agenda of the EU. The Forum was an initiative of Epilepsy Advocacy Europe (EAE) a collaborative joint Task Force of the ILAE and the International Bureau of Epilepsy (IBE).¹¹ The Forum's 7th Framework Program had a goal to further move the agenda outlined in the Written Declaration of Epilepsy approved by the European Parliament in 2011. According to this declaration 6 million citizens in Europe have epilepsy, many of which have difficulties at school, and are victims of high level of unemployment, stigma and prejudice. The purpose of this declaration was among other things to call on the European Council to encourage diagnosis, treatment in all Member States, to ensure equal quality of life for people with epilepsy, and call on the Member States to introduce appropriate legislation to protect the rights of people with epilepsy.

Since social exclusion and stigma largely con-

tribute to the global burden of epilepsy, and they are due to the lack of public awareness of the nature of the disease, it is inevitable to raise public awareness on the topic of epilepsy. Children may be banned from school attendance, adults from concluding legal marriages, women have restrictions in their legitimate right to pregnancy, and employment is often denied, even when seizures do not render the work unsuitable or unsafe. In our study as well most of the patients complained for having had problems at work (20.6%), mainly because of stigma and some because of reoccurrence of seizure. Hence we have come to the conclusion that employers should put more effort in understanding the type of disease and nevertheless where appropriate help these persons to transfer to another working place adequate for them. Additionally 44,1% of patients reported having had social problems, some of which had been rejected from college admission, classmates, colleagues, family and friends. Further to this 13% of patients had problems with obtaining or renewal of their driver's license, a number of which required it for the purposes of their work. Hence precise steps have to be taken with this regard by the National League of Epilepsy, in collaboration with the Automoto Union of Macedonia, in gaining forces to proposing a regulation that would fit the needs of this group of people and assist them in making use of their right. Criminal law problems during attacks are reported in 4,2% of our patients, which were mostly due to confusion and resistance during a seizure episode. Automatic episodes of aggressive or violent behavior may occur during or after an epileptic attack, and this are regarded by the law as insane automatisms.

We have concluded in our study that a vast majority of work needs to be done in our country in order to elevate the level of awareness for epilepsy and the basic rights of people suffering from it. Primarily the initiative should be raised from the National League of Epilepsy¹² together with advocacy organizations and the help of the National Ombudsman, that would further lead to better understanding on the topic by various members of the community and lobbying for the support of healthcare providers to improve the knowledge and change perceptions on the large scale.

The awareness should be heightened and changes still need to be made by addressing this

9 Ibid, at 7: <http://www.ncbi.nlm.nih.gov/pubmed/3720715/>

10 <http://www.ibe-epilepsy.org/wp-content/uploads/2014/04/Final-Report-ERF-12nov1.pdf>

11 Baulac, M., de Boer, H., Elger, C., Glynn, M., Kälviäinen, R., Little, A., ... Ryvlin, P. (2015). Epilepsy priorities in Europe: A report of the ILAE-IBE epilepsy advocacy Europe task force. *Epilepsia*, 56(11), 1687-1695. doi:10.1111/epi.13201

12 <http://www.ilae.org/visitors/chapters/Chapter-select.cfm?countryid=187511ED-9C4C-11DF-F2F51F3AFBE65644>

and including it in the national legislation, a joint work of a team of medical doctors and lawyers. Also when patients with epilepsy and/or related conditions are unable to work, financial benefits should be available to ensure better life of these people. Changes in the current law to the rights of patients and improvement of the existing national healthcare program concerning this problem, need to be made as soon as possible protecting the basic human rights of this group of patients.

Conclusion

Our study confirmed that patients with epilepsy still face stigma and prejudice and as a result experience problems in social inclusion, employment, family matters, and criminal law issues. It is therefore necessary to make reforms in the national health care system to improve the quality of life of these patients. The European written Declaration on epilepsy and the joint work of the Epilepsy Advocacy Task Force should be a good framework and example to follow on how to improve their rights and ensure equality of the quality of life of these patients.

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