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Social and economic aspects of epilepsy

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The history of epilepsy is over four thousand years old. Some historic texts indicate that it is one of the oldest known human diseases. The name comes from the Greek word *epilamvanein*, meaning: to attack, hold, possess, overcome. The term *epilepsia* has been used for 2500 years. Descriptions of the disease are found in the Code of Hammurabi and in the Old Testament. In the past, people affected by epilepsy were considered to be possessed by demons, endowed with some special powers or saints. The true milestone on the way towards diagnosis and therapy of epilepsy was the conclusion made by Hippocrates in 400 A.D. who stated that epilepsy is a brain disease due to natural causes, that must be treated with diet and medication [6].
Opinions of aetiology of epilepsy have changed throughout centuries. At present we have some incomplete knowledge on possible causes of epileptic attacks, their mechanism, and methods of prevention and treatment, thus improving patients’ comfort of life.

From the clinical point of view epilepsy is a syndrome of somatic, vegetative and mental symptoms occurring as a result of recurrent brain dysfunctions. Symptoms of an attack depend on which functional and anatomical area of the brain is affected by abnormal bioelectric activity.

Epilepsy is also a social problem. The fact is associated with the scale of prevalence: nearly 1% of population is affected, and with the chronic character of the disease. The number of epilepsy patients in Poland is estimated at 300-400 thousand, and in the world there are approximately 50 millions of people with epilepsy. A mean prevalence rate of 50-70/100,000/year is evaluated. That means that a number between 20 thousand and 28 thousand of new cases appear every year in Poland. The prevalence rate is age-dependent, increasing over the age of 65 and reaching 250/100,000/year, exceeding the number of new cases in the paediatric population below 10 years [6].

Epilepsy is also the most common neurological problem occurring in paediatric population. The course of clinical presentation of epilepsy in children is different from adult. Prevalence of epilepsy is particularly intensified during the first decade of life – that is the period of critical importance for education and social development. It is reported that in 50% of cases of the condition, the first attack occurs before the age of 11 years, and in 70% of cases – before the age of 14 years. Six per 1000 children suffer from epilepsy during the first decade of life [11].

SCHOOL PROBLEMS AND EPILEPSY

In epilepsy, besides the problems associated with frequency and control of seizures, there are also cognitive, behavioural and emotional disorders that may result in, among others, school problems. Co-existent school problems are a result of organic injuries associated with the disease, its course, applied pharmacotherapy as well as environmental factors, educational activities and the level of patients’ own activity. They have a form of constant or evolving deficits.

Various learning problems may occur in 5 to 50% of epileptic children. School-related problems stem from oculomotor coordination deficits, memory and attention related problems, logical reasoning disorders, increased reaction time, delayed dynamics of cognitive processes and dyslexia, dysgraphia and dyscalculia [12,18].

Just like any other chronic disease, epilepsy causes child’s dependence on its environment, introduces numerous limitations and prohibitions, hinders social relations, disrupts peer relations, causes mental suffering and emotional imbalance. Presence of an epileptic child in a pre-school or school puts a teacher in the position of responsibility for that child’s educational success, but also in the position of legal
responsibility resulting from being a temporary guardian of its safety and wellbeing [16].

Results of Polish and European studies evaluating teachers’ knowledge of educational problems of epileptic students are disturbing. Majority of respondents gave erroneous or “do not know” answers to questions in that field [10, 14].

Teachers have to understand basic aspects of the disease, its mechanisms and effects on child’s everyday function. Teachers have to have an appropriate knowledge to be able to notice problems and correctly satisfy needs of epileptic children. Also a close cooperation between various child’s environments is necessary to provide a support for stable social function. Only comprehensive and complex help may bring some satisfactory effects measured by school, personal and social success [11].

EPILEPSY AND PHYSICAL ACTIVITY AND SPORTS

There is a common belief that physical activity should be limited in epileptic patients. Generally, there are only few forms of non-professional activity that are prohibited to epileptics. However, individual risk and benefit analysis should be made before a particular form of physical activity is suggested to a patient. If attacks are well controlled and uncommon, there are no contraindications for cycling, skiing, skating, tennis, soccer or other contact sports. Swimming and water sports require direct supervision. Certain precautions should always be taken, including technical protective equipment such as kapoks, lifejackets, cycling helmets, etc. That is because of a theoretical risk of an attack. Even with controlled disease a patient should avoid extreme sports and those professional sports, where even a short lapse of consciousness could be fatal or dangerous (diving, gliding, parachuting) [4, 6].

EPILEPSY AND DRIVING

Patient’s own safety and safety of other people is a principal concern. There is no doubt that even a short disturbance of consciousness poses a serious risk. For any accident caused by an epileptic attack the patient would be fully responsible in terms of criminal and civil law. Epilepsy is a chronic disease and patients are perfectly aware of that fact that its main symptoms are seizures associated with loss of consciousness. In some circumstances, e.g. in case of concealing the fact of being ill, or driving despite of the disease, the responsibility may be more strict and threatened with higher criminal penalties.

An amendment of the Regulation of the Minister of Health of the year 2004 regarding medical examination of drivers and candidates for drivers came into power in July 2011. The regulation significantly changed the position of epileptic patients. It should be mentioned that the amendment was a result of EU recommendations and aimed at harmonisation of the Polish law with the norms in power in the Community. The Regulation involves also young people, age 16 to 18, with driving licences category A1 and B1 allowing driving motorbikes up to 125 cc engine capacity and cars below 550 kg of weight.
According to previous regulations, epilepsy was considered a contraindication for driving or applying for driving licence. However, the contraindication was not absolute, because a doctor could allow driving following consideration of a particular health condition. The legislator provided however no health-related criteria for doctors making the decision, and recommendations and instruction practically made positive decisions impossible. That has significantly changed and current provisions are more precise. At present, a doctor who makes a decision, following diagnosis of some neurological dysfunctions defined in the Regulation, refers a patient to a neurologist [3].

For the needs of making decision regarding the inability to drive, epilepsy is diagnosed in case of at least two epileptic seizures within five years, with an interval of over 24 hours. In that case the deciding doctor refers a patient to a neurologist. Epilepsy consistent with the above mentioned criteria results in absolute prohibition to drive and possessing driving licence categories C, C1, D, D1, C+E, D+E, D1+E (trucks, buses, trams and trolleybus), absolute prohibition of professional driving of motorbikes, cars, vans and tractors (categories A, A1, B, B1, B+E, T) [15].

Despite the above mentioned limitations, new regulations introduce a favourable change for part of epileptic patients – it is now legal to drive motorbikes, cars and vans (up to 3.5 tons) and tractors for private purposes (categories A, A1, B, B1, B+E, T). To be able to get the non-professional driving licence a patient has to be asymptomatic for one to two years, depending on the course of his/her disease and therapy, and to have control visits to a neurologist. Intervals between those visits are defined in the Regulation.

If a neurologist decides on discontinuation of anti-epileptic drugs, there is an absolute prohibition of driving for 6 months, and further neurological evaluations for next 5 years. In case of a modified treatment a neurologist is able to determine a period of driving prohibition.

Any doctor who diagnoses epilepsy or even has a suspicion of epilepsy is obliged to notify the licensing organ about the fact. The organ refers a patient for neurological control, and makes a decision according to the above mentioned principles dependent on the result of the control [15].

Following meeting the above mentioned criteria a patient may receive a time-limited driving licence. Its renewal requires a neurological control.

A new driving licence category – AM – was introduced on 19 January 2013. The driving licence allows driving mopeds, scooters and quads. The group involves single- and double-track vehicles equipped with an engine (including an electric one) up to 50 cc capacity, up to 4 horsepower, and top speed limited to 45 km/h.

People over 14 may apply for the driving licence category AM. The licensing procedure involves medical examination, training and exam at the District Traffic Centre. It is not known yet what restrictions will be introduced by a new Regulation of the Ministry of Health for epileptics. Probably the limitations will be similar as for adults, with consideration to the specific features of developmental epilepsy. The new driving licence will be issued for a definite period of time, up to 15 years.
Currently valid moped cards will be exchanged to the new AM driving licence without a required training and exam. However, it is not known if there will be an obligatory medical examination, because no executive provisions have been issued yet.

People who are over 18 before the new provisions of law come into power have the right to dive those vehicles according to the previously valid law (in the territory of Poland only) – that is without the AM driving licence or any other licence [3].

It should be mentioned, however, that contrary to cars, mopeds and scooters offer no passive protection for a driver, and a fall at 30–40km/h may cause some serious injuries, or even death. Therefore, in case of epileptics it seems justified to apply the rules that came into power in July 2011.

In case of riding a bicycle on public roads, adults do not need any licence, and therefore are exempt from any medical examination. On the other hand, children aged from 10 to 16 riding a bicycle on public roads have to have a bicycle card.

A bicycle card is issued by a schoolmaster following an exam organised by an authorised teacher or a policeman, and with absence of general contraindications for riding a bicycle. The law does not provide a precise definition of those general contraindications, but they may involve any emotional disorders, mental and physical immaturity and diseases (including epilepsy) that a teacher or a policeman may be aware of (teachers are generally well informed by parents). The problem could be solved by an appropriate medical or psychological certificate, but the issue remains unregulated by the law and therefore the examiner is entitled to refuse issuing a positive decision [3].

Riding a bicycle by epileptics, regardless their age, is not regulated by any provisions of law. Formally there are no contraindications. From the medical point of view recreational biking is also possible in a group of patients with sporadic seizures, and provided some safety precautions are met. Therefore, riding in a company of a health person able to help in case of emergency, on bicycle routes or public roads with minimum traffic, with low speed, in favourable weather, with moderate effort, always in a helmet and sunglasses is recommended.

**EPILEPSY AND PROFESSIONAL ACTIVITY**

Choice of a profession is a very important question. People burdened with the disease should be professionally active. However, epilepsy is associated with numerous contraindications associated mainly with safety of a patient and his/her neighbourhood, in case of lapse of consciousness. Patients should not work on heights and in shifts, they should not operate machinery or electricity-generating devices. Driving is contraindicated, and work in a close vicinity of water basins, sources of fire, chemicals. They should not use weapons. Additionally, patients at risk of sudden loss of consciousness should not be left alone at their work stand.

A work in form of a monitor screen is doubtful, especially in case of photosensitive patients. A photo-convulsive response does not necessarily indicate epilepsy. Two percent of patients with other diseases develop hypersensitivity to light stimuli. However, it may be stated that photo-sensitivity indicates a predisposition to
epilepsy, and in vast majority of cases is genetically determined. (...) In sensitive people, flashes of 15 to 20 cycles per second appear to be critical. LCD screens with no image refreshing cycles is not dangerous. No light-hypersensitivity problems are also associated with monitors with over 100 Hz refreshing rate, because human eye cannot receive image dots at the frequency of over 90 Hz, and the whole image is received as one whole. Therefore, an epileptic patient requires a detailed analysis of a type of a monitor he/she should operate, as well as careful evaluation of the type and course of the disease, EEG and history of possible provoked events by a neurologist [17]. Employment is another important question for epilepsy patients. It is estimated the social stigmatisation is a more serious problem that seizures itself, and that it is a most important factor accounting for deterioration of quality of life of those patients. The fear of discrimination is so high, that they often conceal their health condition at work [5].

In February and March 2013 a PRO-EPI study entitled “To understand epilepsy at work” was organised by TNS Polska, under auspices of the Polish Society of Epileptology and the pharmaceutical company UCB. The study recruited a representative group of neurologist (N=145) and adult epilepsy patients (N=861). The applied methodology was: direct interview (with doctors) and surveys (for patients).

The study demonstrated that only 40% of epilepsy patients is professionally active. The employment rate in Poland during the 4th quarter of the year 2012 was 65.7% of people in productive age. Twenty four percent of epileptic patients have never worked. In the study, 73% of the surveyed subjects admitted that epilepsy was a cause of numerous concerns and anxiety in everyday life, and restricts patients’ chance for education, hobbies and interests, social functioning, as well as influences the chance for employment and maintenance of work. Unemployed patients indicate the disease itself as the main cause of their unemployment (36%): difficulties with finding a job, risk of losing the job because of the disease, concerns about lack of acceptance at work and being treated as a disabled person, and anxiety that no one will be able to help them in case of a seizure at work. Epileptic patients often conceal their condition from the employer and co-workers. They are often discriminated at work, because many people have insufficient knowledge of the disease. However, being able to work is not only being able to earn, but also plays a very important role as a factor increasing self-evaluation and the sense of being a part of the society. That is why helping patients with finding and maintaining a job is so important. Nearly 60% of currently unemployed patients declare that would like to have a job in a future. Another 12% declare their will to start a job if they were free from epileptic attacks. Those results are confirmed by participating doctors, who believe that regardless the age, the number of professionally active epileptic patients could be higher if seizures could be eliminated [13].
EPILEPSY AND COSTS OF TREATMENT

Costs of treatment and medical support for epilepsy patients incurred by the patient and by society are high, both in Poland and abroad. They are higher compared to the costs of medical care and treatment of non-epileptic patients [1].

According to WHO data, epilepsy-associated burden is high, and in 2000 constituted approx. 0.5% of costs of all diseases in the world [7]. In Poland, expenditures of the Health Fund (NFZ) on medication reimbursement for 18 chronic diseases constituted 45% of the total sum of reimbursement for all drugs in 2004. Among those 18 chronic diseases epilepsy was on the 4th place, with 4.89% of expenditure on refunded drugs, and the 1st place among neurological conditions (Majkow-Obecny). A prospective, multicentre study of annual direct and indirect costs of epilepsy in Poland, the main cost-inducing factors were: frequency of seizures, duration of epilepsy, novel anti-epileptics (45% of all drugs), polytherapy, hospitalisations and coexistent diseases [6, 9].

Costs of an effective treatment of epilepsy, even with an expensive drug, are lower than costs of improper therapy. Indirect costs resulting from social restrictions and loss of productivity are the main category of epilepsy-associated costs, both in Poland and abroad [2, 13]. Data from Social Security Agency (ZUS) in 2011 indicate that expenditure associated with work disability of epilepsy patients constituted 1.2% of overall costs – that is approx. PLN 340 million. Those expenditures involved mainly the, so called, indirect costs, including pensions for unemployed patients. An average length of a sick leave in epilepsy patients in 2012 was 30 days [13].

In an attempt to face the situation in which 6 millions of people in Europe suffers for epilepsy, causing an annual loss of EUR 20 billion for the European economy and causing 13 thousand deaths (40% of which would be avoidable with correct diagnosis and treatment) the International Bureau of Epilepsy (IBE) and the International League Against Epilepsy (ILAE) supported by operation of the European Group for Epilepsy at the European Parliament, cooperate to create the first European program for epilepsy that would improve prophylaxis, care and quality of life of epilepsy patients in Europe. The first effect of that cooperation is the European Declaration on Epilepsy passed in the European Parliament in September 2010 [6].

Epilepsy patients require understanding and appropriate help from the society, as well as correct treatment aimed at elimination of seizures. That is possible due to increased availability of modern anti-epileptic drugs. Effectively treated patients will become valuable labourers, leading normal professional and social life.

REFERENCES

11. Michalska A. i wsp.: Świadomość obecności problemów zdrowotnych i edukacyjnych uczniów z padaczką wśród nauczycieli z terenu województwa świętokrzyskiego. Neurologia Dziecięca 2012; 21(42):32-33
12. Mojs E i wsp.: Występowanie zaburzeń poznawczych i emocji w padaczce i ich implikacje dla terapii. AAMS 2007; 53: 82-87
15. Rozporządzenie Ministra Zdrowia z dnia 15 kwietnia 2011r zmieniające rozporządzenie w sprawie badań lekarskich kierowców i osób ubiegających się o uprawnienia do kierowania pojazdami. Dz.U.2011 nr 88 poz 503 zał. 4
ABSTRACT

Epilepsy is a serious and common neurological condition of both adults and children. Besides medical problems, epilepsy patients encounter also social and legal problems and limitations. The paper discusses the most common issues associated with a school, physical and professional activity, valid driving regulations in the aspect of epilepsy. Economic issues associated with epilepsy are also presented.

STRESZCZENIE

Padaczka jest poważnym i częstym schorzeniem neurologicznym zarówno u dorosłych jak i dzieci. Poza problemami medycznymi chorzy cierpiący na padaczkę spotykają się na każdym etapie swojego życia z problemami oraz ograniczeniami o charakterze społecznym czy prawnym. W pracy omówiono najczęstsze problemy dotyczące szkoły, aktywności fizycznej i zawodowej, aktualne zasady dotyczące prowadzenia pojazdów w aspekcie padaczki. Przedstawiono również zagadnienia ekonomiczne związane z padaczką.

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