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## **Knowledge of epileptic patients about the disease**

## **Wiedza chorych z padaczką na temat schorzenia**

### **Summary**

**Introduction:** The history of views on epilepsy and its treatment is a reflection of the mental development of mankind: the level of knowledge, culture and social relations. In ancient times, people suffering from epilepsy were considered to be possessed, and thus subject to different spells, rituals and to an exorcist in order to get rid of the demon from their bodies. Many other methods were also used then that do not apply today.

**Aim:** The aim of this study was to determine the level of knowledge of epilepsy patients about their disease.

**Material and Methods:** The study was conducted within 2 months of 2007, among patients of Outpatient Regional Specialist Hospital in Białystok, using a questionnaire especially prepared for the construction of the work objectives.

**Results:** The study group consisted of 30 patients diagnosed with epilepsy. Almost half of the respondents (43.4%) were granted disability pension because of epilepsy. Among the 76.6% of the respondents, there were no cases of epilepsy in the family. The vast majority (63.4%) of respondents identified as sufficient their level of knowledge about the procedure at the time of an epileptic seizure. The respondents gave the correct answer on the proceedings at the time of a seizure. Among the respondents, 76.6% of people informed their families how to behave during an epileptic seizure. Half of the respondents felt that the biggest problem in the functioning of daily life of patients with epilepsy is a limited contact with others, and 46.6% of people pointed out other problems, among others fear of an attack in a public place.

**Clinical Implications:** The level of knowledge among respondents about epilepsy is satisfactory, and patients expect from nurses mainly support and tips about living with epilepsy. The lifestyle of patients with epilepsy has not changed much, despite the fact that most patients are afraid of an epileptic attack in a public place.

**Key words:** epilepsy, knowledge

### **Streszczenie**

Historia poglądów na padaczkę i jej leczenie jest odbiciem rozwoju umysłowego ludzkości: poziomu wiedzy, kultury i stosunków społecznych. W dawnych czasach ludzie chorzy na padaczkę uważani byli za opętanych, a co za tym idzie poddawani różnym zaklęciom, rytuałom i egzorcystyce, aby pozbyć się demona z ich ciał. Stosowano też wiele innych metod, które nie mają zastosowania w dzisiejszych czasach.

Celem pracy było określenie poziomu wiedzy pacjentów z padaczką na temat ich choroby.

Badania przeprowadzono w okresie 2 miesięcy 2007 roku wśród pacjentów Poradni Padaczkowej w Wojewódzkim Szpitalu Specjalistycznym w Białymstoku za pomocą kwestionariusza konstrukcji własnej sporządzonego dla celów pracy. Grupę badawczą stanowiło 30 pacjentów ze zdiagnozowaną padaczką. Prawie połowa badanych (43,4%) przeszło na rentę z powodu padaczki. Wśród 76,6% ankietowanych, nie występowała padaczka w rodzinie. Znaczna większość (63,4%) badanych określiła jako wystarczający poziom posiadanej wiedzy na temat postępowania w czasie napadu padaczkowego. Ankietowani udzielali poprawnej odpowiedzi odnośnie postępowania w czasie napadu padaczkowego. Wśród badanych 76,6% osób, poinformowała swą rodzinę jak należy postępować w czasie napadu padaczkowego. Połowa ankietowanych uznała, że największym problemem w funkcjonowaniu w życiu codziennym chorych z padaczką jest ograniczenie kontaktu z innymi, a 46,6% osób wskazało na inne problemy m. in. obawę przed wystąpieniem ataku w miejscu publicznym. Poziom wiedzy, wśród ankietowanych na temat padaczki jest zadowalający, a chorzy oczekują w głównej mierze od pielęgniarzy przede wszystkim wsparcia oraz porad dotyczących życia z padaczką. Styl życia pacjentów z padaczką nie uległ większym zmianom, pomimo, iż pacjenci w większości obawiają się wystąpienia ataku padaczkowego w miejscu publicznym.

**Słowa kluczowe:** padaczka, wiedza

Epilepsy is one of the most difficult neuro-epidemiological problems. It is estimated that approximately 50 million people worldwide suffer from epilepsy. In Poland, epilepsy occurs in about 1% of the general population. The rate of new cases in Poland amounts to 50-70 patients in 1000, 000 in a year. This means that every year, there are between 20 000 and 28 000 new cases of epilepsy (Drazkowski, 2004).

A seizure is an expression of altered reactivity or modified physiological state for the whole or part of the brain. One attack is not an epilepsy. The condition can develop in people of all ages, formed as a result of one-or multifocal lesions at various sites and has diverse etiology and morphology of seizures and electroencephalographic recordings and other intricate and controversial classification (Drazkowski, 2004), (Ryglewicz, Kuran, 2003).

Some environmental, genetic and physiopathological factors foster the creation of epileptic seizures, but some reasons for acting in adult patients do not occur at a younger age (Ryglewicz, Kuran, 2003).

One of the goals of treatment is to reduce the number of epileptic seizures or their complete elimination (Zubiel, 2006). Therefore, a number of newer pharmacological or surgical methods increases, and also some alternative therapies like homeopathy and aromatherapy.

Patients with epilepsy suffer from mental health problems. They fear the risk of seizure in public. They have difficulties in dealing with the environment, studying, getting work, they feel uncomfortable in interpersonal relations, etc. (Kłos, Zielinska, 2006; Koncewicz, 2006). Patients may have certain occupations, and their way of life requires some sacrifices. Therefore, it is also necessary to educate patients and their families concerning the avoidance of factors triggering seizures, the procedures during seizure and health behaviours (Pizzini et al. 2001; Drazkowski, 2004).

The aim of the study was to determine the level of knowledge of epilepsy patients about their disease. The following specific objectives were formulated:

- 1 Assessment of the level of knowledge of epileptic patients about the disease.
- 2 Defining expectations of epileptic patients towards nurses.
- 3 Defining changes in daily life of patients with epilepsy.
- 4 Defining problems in patients with epilepsy

**Material and Methods:** The study group consisted of 30 patients (of both sexes diagnosed as epileptic) of Epilepsy Counselling Clinic in Regional Specialist Hospital in Bialystok, at the age of 18 -75 years. The conducted study was based on the original questionnaire. Questions related to demographics, social and living conditions of patients with epilepsy, the problems of patients with epilepsy, the scope of knowledge and the level of demand for education.

## Results

The study group consisted of 30 people diagnosed with epilepsy, of which 18 (60%) were male and 12 (40%) women. Respondents' age ranged between 18 and 75 years of age. Persons under 30 years of age accounted for 50% of patients. Most patients, 14 (46.7%) live in towns more than 10. 000, 11 (36.7%) of people lived in villages, while the remaining five (16.6%) patients, lived in towns of less than 10 000 inhabitants.

The largest group of respondents consisted of patients with secondary (46.7%) and vocational education (30%). 13.3% had primary education and 6.7% higher education. Only 3.3% of respondents had special needs education. 36.6% were learners, while those working professionally accounted for 20%. Almost half of the respondents (43.4%) got disability pension because of epilepsy. Among the 76.6% of the respondents, there was no epilepsy in the family. In the majority (60%) of patients the first seizure occurred at the age of six years, between the ages of 3 -5 years of (30%) patients. In only 10% of people the first seizure occurred before 2 years of age. 90% of respondents have been treated for more than 6 years because of epilepsy. Only 6.7% have been treated for 3-5 years (Table 1).

Tab. 1. Diagnosis and treatment of epilepsy

| Range         | First seizure |              | Diagnosis period |              | Treatment period |              |
|---------------|---------------|--------------|------------------|--------------|------------------|--------------|
|               | N             | %            | N                | %            | N                | %            |
| 0-2 years     | 3             | 10           | 23               | 76,7         | 1                | 3,3          |
| 3-5 years     | 9             | 30           | 7                | 23,3         | 2                | 6,7          |
| Above 6 years | 18            | 60           | 0                | 0            | 27               | 90           |
| <b>Total</b>  | <b>30</b>     | <b>100,0</b> | <b>30</b>        | <b>100,0</b> | <b>30</b>        | <b>100,0</b> |

Only 23.4% of people know what type of epilepsy was diagnosed in them (Figure 1).

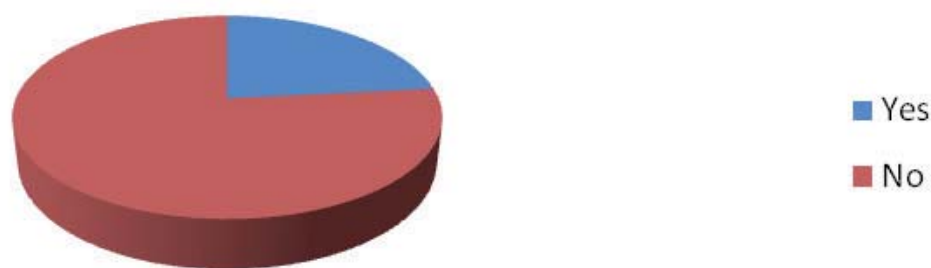


Fig. 1. The knowledge of the type of seizure by the respondents

Respondents asked about the factors conducive the occurrence of seizures most frequently mentioned the lack of sleep (53.3%), anxiety (50%), watching television (20%), excessive sleep (6.6%), strobe light (6.6%), and 43.3% of people reported other reasons (Figure2).

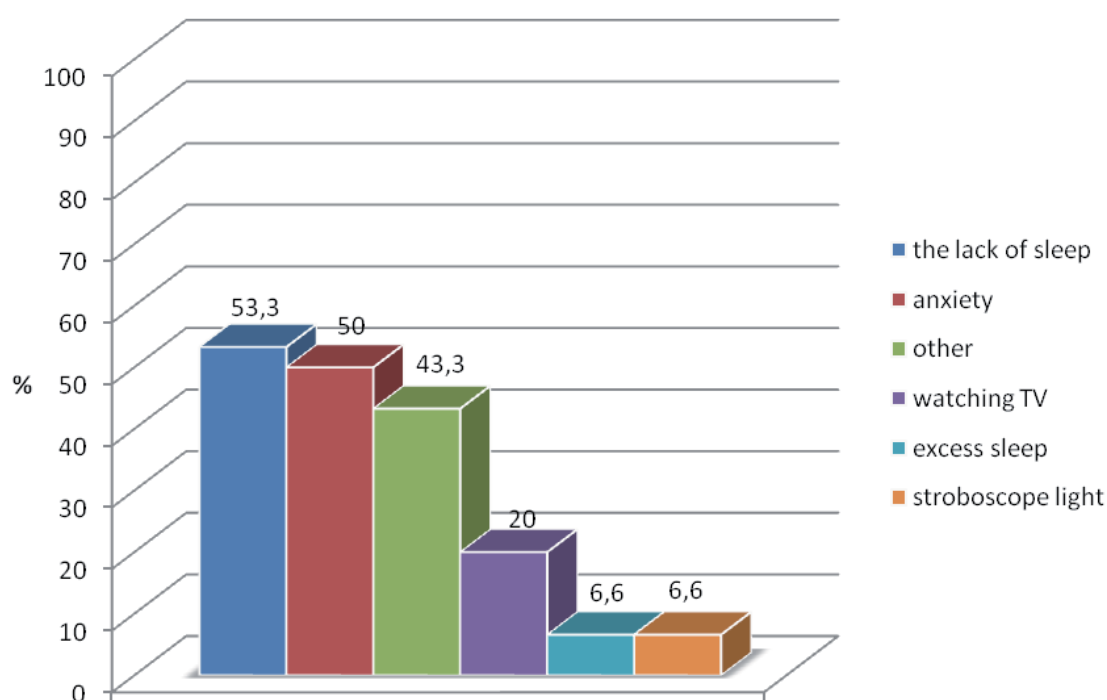


Fig. 2. Factors contributing to the occurrence of seizures.

According to most respondents medicine must be taken regularly (93.4%). Only one person said that only at the time of the seizure, and 3.3% did not know how to take medicine.

Once within two months 76.6% visit the outpatient epileptic clinic, 16.7% once a month, and 6.7% every six months (Table 2).

Tab. 2. Visits to the epileptic clinic

| <b>The frequency of visits</b> | <b>N</b>  | <b>%</b>     |
|--------------------------------|-----------|--------------|
| Once w week                    | 0         | 0            |
| Once a month                   | 5         | 16,7         |
| Every six months               | 2         | 6,7          |
| Once a year                    | 0         | 0            |
| other (every two months)       | 23        | 76,6         |
| <b>total</b>                   | <b>30</b> | <b>100,0</b> |

The vast majority (63.4%) of respondents identified as sufficient the level of knowledge about the procedure at the time of seizure, while 36.6% of people said they did not have any knowledge on this subject. Respondents asked about the treatment at the time of seizure, in the vast majority (96.0%) mentioned that the patient should be placed in a safe position, something should be put under his/her head, and do not hold the patient's body during an attack. However, 4.0% of respondents reported that one should not hold the patient during an epileptic seizure and seek specialist help. Among the respondents, 76.6% people informed their families how to behave during an epileptic seizure.

Half of the respondents (50.0%) stated that the occurrence of epilepsy did not affect their working life, because either they do not work or did not inform the employer about the disease. The disability pension because of epilepsy have over 40.0% of individuals and 6.7% of the respondents have given up their jobs, only 3.3% of respondents changed jobs (Table 3).

Tab. 3. Impact of the disease on working life

| <b>the impact of the disease on professional life</b> | <b>N</b>  | <b>%</b>     |
|-------------------------------------------------------|-----------|--------------|
| Job changing                                          | 1         | 3,3          |
| Resignation from work                                 | 2         | 6,7          |
| Getting a disability pension                          | 12        | 40           |
| Others                                                | 15        | 50           |
| <b>Total</b>                                          | <b>30</b> | <b>100,0</b> |

Only 20.0% of people carry a tag with information about the disease.

Only 10.0% of respondents attend meetings of organizations of patients with epilepsy. However, 90.0% of respondents do not use the help of any associations. The majority (93.3%) patients obtain information about their disease from doctors and nurses, (13.3%) from television, (10.0%) from newspapers, (20.0%) from the Internet (30.0%) (Figure 3).

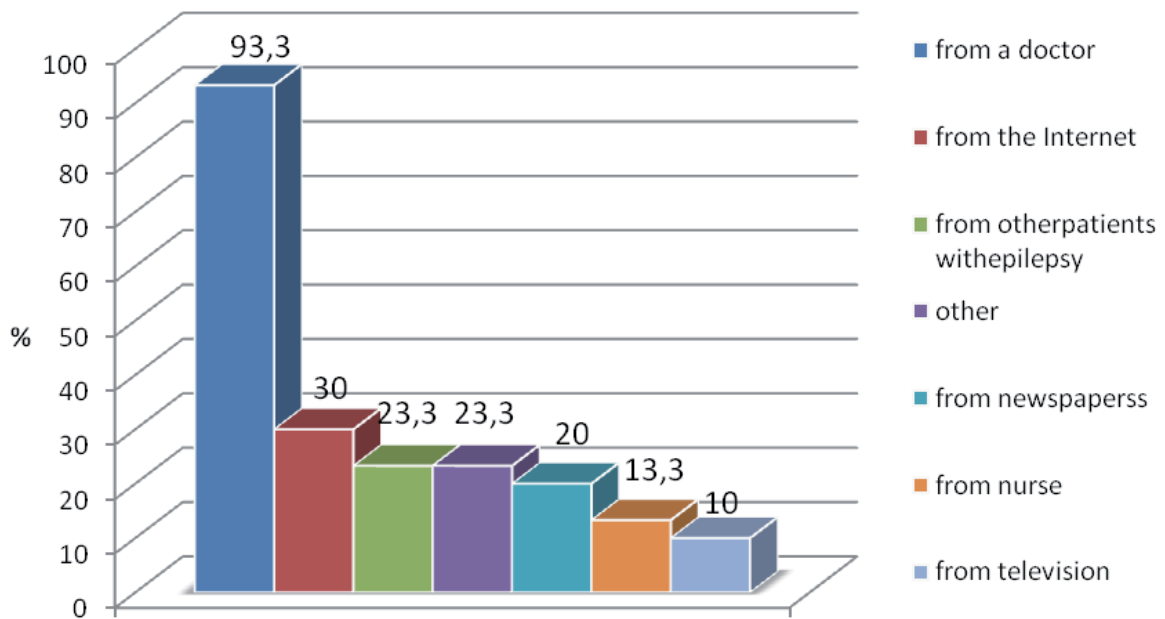


Fig. 3. Sources of information about epilepsy.

The desire to raise awareness about their condition was expressed in more than half of the respondents, only 13.3% of people believe that they have sufficient knowledge on the subject. The majority of respondents (73.3%) expected advice and support from a nurse (63.3%). 36.6% wants to get information on job opportunities, and information on opportunities for practicing sports is expected by 26.6% of patients with epilepsy. However, 16.6% of people expect information on existing associations of patients with epilepsy (Figure 4).

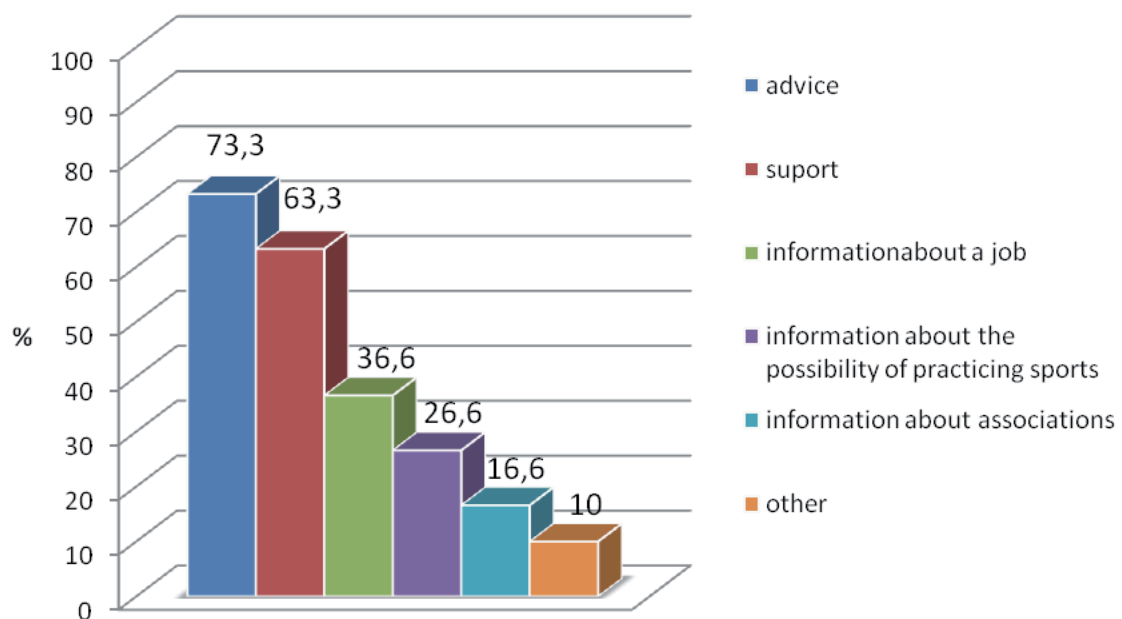


Fig. 4. Information sought from nurses.

Half of the respondents felt that the biggest problem in the functioning of daily life associated with the disease is a limited contact with others. The need to comply with medical recommendations was a problem for 13.3% of people. However, 46.6% indicated other problems, among others occurrence of an attack in a public place and the lack of awareness of the environment for the conduct of patients with epilepsy during the attack (Figure 5).

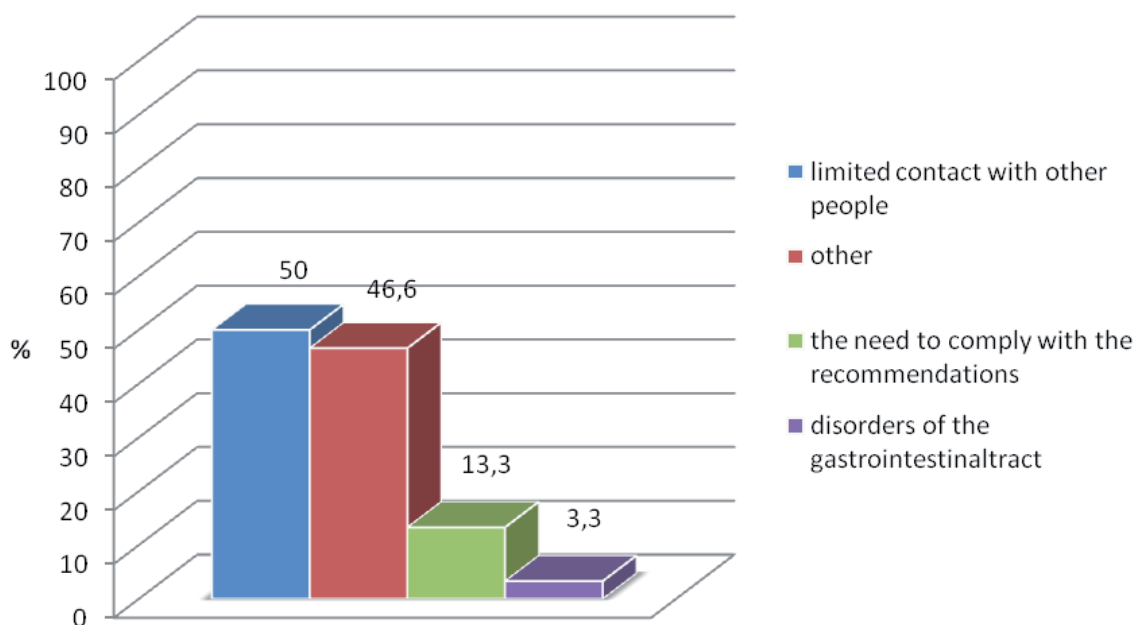


Fig. 5. Problems of patients with epilepsy

### Discussion of results

The level of knowledge of patients is an important factor in the treatment of patients with epilepsy. Patients with epilepsy experience a range of psychological, physical and social problems, and therefore the increase of the level of awareness among patients and the closest surrounding can help to optimize care of this population of patients, allowing to single out patients who require help of a psychologist, nurse, etc.

Literature does not provide unambiguous triggers of epilepsy. Zyski and Prusiński show that anxiety, alcohol, lack or excess of sleep, stress, hormonal changes, injuries, perinatal, family and birth defects of the brain, metabolic defects are all causative agents of a seizure (Owczarek et al. 2007; Ryglewicz, Kuran, 2003). In our study, patients found the lack of sleep (53.3%), anxiety (50%) and watching television (20%) as the main factors favoring the occurrence of seizures.

In our study, it was found that the first seizure occurred before the age of two in 10% of the cases, while in the remaining 60.0% of patients, the seizure occurred above 6 years of age. The results confirm the findings of other authors (Malińska et al. 2007; Drazkowski, 2004).

The consequence of the disease in many cases is the constant application of drug therapy to prevent the occurrence of seizures (Kapinos et al. 2006). In their own studies it was found that the majority of respondents (93.4%) take medication regularly but older people cannot remember the names of medications.

In recent years, the approach to undertaking work by people with epilepsy is changing. The results of comparative studies in the U.S. show that in 1994 only 45% of the Americans thought that people with epilepsy should work professionally, but in 1997 the proportion had risen to 79% (Owczarek et al. 2007).

The feelings of patients due to the fact of seizures are usually very hard. People with epilepsy experience fear of seizure, shame, they fear that the attack may occur in a public place. They are often accompanied by a sense of being “different”, being a subsidiary to others. Living with the awareness of the possibility of an attack and in a kind of “waiting” for a seizure means that the patient has no sense of control, has reduced efficiency and even the state of frustration, a sense of complete submission to the disease (Wilusz, Landowski, 2007; Zielińska et al. 2006).

In the study of Kapinos et al. 77.5% of the respondents felt that people with epilepsy should inform their milieu about their disease, but only 52.1% of respondents would tell their friends about the disease in their family. In the same study, 51% of the students said that people with epilepsy can have the same job as healthy people, but 14.8% of respondents would dismiss such a person if a seizure occurred during working hours (Kłos, Zielinska, 2006; Owczarek et al. 2007). Analyzing the research it has been shown that the occurrence of epilepsy did not significantly influence the respondents working life. However, the pension because of epilepsy got 40.0% of people, while the others changed job or quit.

The research shows that people have insufficient knowledge about epilepsy in order to assist patients during seizures. People with epilepsy are also concerned about public response to their illness. Therefore they often hide this fact. This is confirmed by studies carried out in a group of middle school students by Zielinska et al., in which, young people do not have knowledge about the first aid during a generalized epilepsy seizure and the level of knowledge depended on the age of the respondents, place of residence and knowledge of a person suffering from epilepsy (Malińska et al. 2007). In a study conducted among students of the Silesian universities, most indicated that they would help a sick person during a seizure, but up to 69.8% of these people would make it wrong (Zielinska et al. 2006).

Patients with epilepsy often suffer the consequences of a negative attitude. The media have a major impact on an attitude of the society towards patients with epilepsy. Therefore publications about epilepsy should be monitored by the medical societies. In the analysis of articles made in 2002-2005 in the press there was no article on first aid during an epileptic seizure. Therefore there is a need to educate the public on the treatment at the time of seizure (Jarzębska, 2006; Kłos, Zielinska, 2006).

Kłos states that young people suffering from epilepsy in the majority is accepted by their peers at school and the disease does not affect much on their leisure time. The youth can also choose a future profession ensuring independent living in adulthood (Zielinska et al. 2006). In the study it was showed that the subjects often have dilemmas as to which sports and jobs they can undertake.

In adapting to the disease a very important role plays the presence of such external sources of support as a family, friends, colleagues, self-help groups. Governmental and non-governmental organizations are important, they can significantly help the chronically

ill to adapt. In Poland, there are organizations for people suffering with epilepsy in professional or social matters, including Polish League Against Epilepsy, Polish Association of People with Epilepsy (Zielinska et al. 2006). Analyzing the own research it was found out that only 10% of people with epilepsy are assisted by associations, which may be due to the fear of disclosure of their disease in their environment or ignorance.

A nurse fulfills a number of tasks in relation to patients to help them recover, for example forms the sense of responsibility for their own health, prepares a patient to make and implement activities to promote health and to prepare a patient for self-care. Therefore one can conclude that a nurse acts as a teacher, educator, educator and also helps him/her solve problems, performs medical orders, and many other activities that are to help improve the health of the patient (Kapinos et al. 2006). The study showed that patients, above all, expect from nurses support and advice, and information about the possibility of practicing sports and the type of profession that can take. One should keep in mind that the purpose of therapeutic interventions is to improve the quality of life of the patients. It is therefore important to meet their needs on an individual basis.

The knowledge that you have about various limitations that are caused by the disease is certainly helpful in accepting the disease and its treatment by patients as one of their features (Kapinos et al. 2006; Koncewicz, 2006). Patient should be encouraged to take up new forms of activities in the workplace, home and school.

Coping with epilepsy is the ability of patients to use their abilities to overcome limitations and difficulties resulting from their disease occurring in everyday life. Therefore, it should be remembered that the purpose of educational activities is to improve the quality of life of the patient.

### **Conclusions**

1. The level of knowledge among respondents about epilepsy is satisfactory. Most patients know the factors conducive to seizure and rules of conduct during it.
2. Patients expect from nurses support and tips about living with epilepsy, particularly doing sports and career opportunities.
3. Lifestyle of patients with epilepsy has not undergone much change, however, the biggest problem in the daily life is a limited contact with others and the need to adhere to medical recommendations.
4. Patients are mostly afraid of epileptic seizures in public, which is caused by the fear of public reaction

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