Current knowledge about epilepsy and associated psychosocial conditions

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SUMMARY

Introduction. Social knowledge about epilepsy has significant influence on shaping attitudes towards people with this disorder.

Aim. The aim of the article was to find out an answer to the following question: How does the level of knowledge and perceiving people with epilepsy differ across societies of different countries?

Material and methods. We evaluated 30 publications published between 2000 and 2013 on measuring the knowledge about epilepsy and psycho-social functioning of people with epilepsy. The articles were divided into five groups (including five continents): Europe-14 articles: six from Poland and eight from other countries, one from New Zealand, five from America, six from Asia and four from Africa.

Discussion and conclusions. Despite widespread occurrence of the disorder in the world, the level of knowledge about epilepsy is low. Most authors, but also respondents, still postulate the necessity to introduce education on the matter to various age groups. The best form of communication used by the respondents is the media

Key words: epilepsy • knowledge • psychosocial conditions

INTRODUCTION

Epilepsy is one of the most often occurring neurological disorders in the world. De Boer et al. (2008) referring to the literature review informs that the epilepsy incidence rate in economically developed countries is from 40 to 70 on 100.000 persons per year, whereas in those developing it is higher - about 120 on 100.000 persons per year. It is usually higher in children and older people. Factors fostering the increase in incidence in poorer countries include: poor sanitary conditions, inefficient health system, increased infection risk of CNS and brain injuries (Sander, 2003; de Boer et al., 2008). This considerable occurrence of epilepsy, however, does not favour social functioning. In numerous studies that take into account various characteristics of the respondents (including i.a. age, sex, ethnic origins, financial situation, education level) the issue of stigma

concerning people with epilepsy is noted (Austin et al., 2002; Doughty et al., 2003; Fernandes et al., 2004; Jacoby et al., 2004; Birbeck et al., 2006). In a study involving 15 European countries 51.0% of respondents reported stigmatization of patients and 18% reported a considerable feeling of stigmatization (Buck et al., 1999; Morrell, 2002). Doughty et al. (2003) claim, on the basis of studies in 10 European countries, there is a high stigmatization among 17% of respondents. The weakest feeling of stigmatization was reported by patients in Holland (27%) and Spain (31%); the strongest in Poland (56%) and France (62%). In studies that analyzed the stigma in people with epilepsy the authors (Baker et al., 1999; Jacoby et al., 2004; Jacoby, 2008) refer to the Goffman theory. This theory states that people become stigmatized when they considerably differ from the rest of the

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society. This difference is perceived as an agent lowering the value of the group. In case of people with epilepsy, such a factor can be seizures or the necessity to intake medication regularly. Factors conditioning the perception of people with epilepsy include: age, sex, education level, knowing a person with epilepsy and being present during a seizure (Kobau and Price, 2003; Jacoby et al., 2004; Bishop and Boag, 2006; Otoom et al., 2006; Zielińska et al., 2006; Mecarelli et al., 2007; Mecarelli et al., 2010). Since knowledge has substantial influence on shaping social attitudes towards people with epilepsy, an attempt has been made to investigate the level of knowledge among people of various nationalities based on available literature.

AIM

The aim of the article was to find out an answer to the following question: How does the level of knowledge and perceiving people with epilepsy differ across societies of different countries?

MATERIAL AND METHODS

In the analysis 30 articles, published between 2000–2013, with content linked to the notion of knowledge, perceiving, attitudes towards people with epilepsy, have been included.

Articles included answers to most of the questions listed below.

For knowledge about epilepsy, the following questions have been considered:

- Have you ever heard or read about epilepsy?
- Do you know a person with epilepsy?
- Do you know the cause of the disease?
- Is epilepsy a mental illness/possession?
- Is epilepsy a contagious illness?
- Do you know factors triggering a seizure?
- Do you know the rules of proper first aid?

For perceiving people with epilepsy, the following questions were considered:

- Can people with epilepsy frequent school together with healthy children?
- Would you agree that your child played with a child with epilepsy?
- Would you agree that your child married a person with epilepsy?
- Can people with epilepsy be employed?

The articles have been divided into five groups (including 5 continents): Europe – 14 articles: six from Poland and eight from other countries, one from New Zealand, 5 articles from America, six works from Asia and four from Africa (Table 1). In the analysis, the following information has been included: title of the journal, the studied group, location of the research, the instrument, knowledge and opinion about people with epilepsy.

REVIEW

The knowledge of the disease specifics and perceiving people with epilepsy in each individual country.

Europe

Poland

Analysis of studies with characteristics of people with epilepsy has been made to investigate the specifics of people with epilepsy group.

Majkowski and coworkers (2003; Majkowski and Majkowska-Zwolińska, 2007) thoroughly characterized demographic, social and medical features of Polish patients in 2001 and 2006. The article comprises results from 19 Polish medical outpatients' centers treating people with epilepsy (Majkowski and Majkowska-Zwolińska, 2007). The average age of patients was 27. One third of the studied group was of school age (up till 18). Females slightly predominated (53.9%). The mean time of epilepsy duration was 12.4 years. 55.8% of the group had secondary or university education. On third was married, 50% lived on pension or attendance allowance. 16.5% were employed, only 3.7% of respondents reported they did not work because of the disorder. Comparison of the studies from 2007 with those from 2000 revealed that the only change was the increase of: people with university education and more frequent treatment with new antiepileptic drugs.

The above mentioned data were supplemented by the results gathered by the international SPOKE project, these results concerned the level of knowledge among people with epilepsy and their families (Niedzielska et al., 2004). 41% people with epilepsy identified that their problems with finding employment was due to their epilepsy. Antiepileptic drugs were taken by 98% of the patients, 81% declared good or quite good control of seizures. The average level of knowledge among patients was 22 on 31 total points. Almost 75% of the group had little knowledge of the disease process. Patients most of all, did not know the aetiology of epileptic seizures. A higher level of knowledge was found in

 Table 1. The list of selected articles about knowledge and psychosocial functioning

Authors	Studied group	Tools	Research area
Majkowski and Majkowska-Zwolińska, 2007	1019 patients with epilepsy aged 3 months to 82 years	Author's own questionnaire	Demographic, social, medical features
Niedzielska et al., 2004	Multicenter research – 10 countries, in total 6156 patients, 6506 carers. 1028 patients from Poland and 1033 carers	The impact of Epilepsy Questionnaire, Adjustment to Epilepsy Stigma scale, The Epilepsy Stigma scale, The Epilepsy Knowledge Questionnaire (EKQ), filled by respondents and carers. Questionnaires were validated in Great Britain	Medical aspects, level of knowledge, disease influence on life, stigma
Kłos et al., 2005	181 students from 2 high schools in Poznań	Questionnaire of own design based on Bekiroğlu et al., 2004	Level of knowledge and at- titudes towards people with epilepsy
Zielińska et al., 2006	79 students from junior secondary school in Poznań and Kłecko	Questionnaire of own design based on Bekiroğlu et al., 2004	Level of knowledge and at- titudes towards people with epilepsy
Zielińska et al., 2009	108 teachers from junior secondary and high school	Questionnaire of own design based on Bekiroğlu et al., 2004 and going literature	Level of knowledge and at- titudes towards people with epilepsy
Siemiński et al., 2002	204 students from 3 high schools in Gdańsk	Questionnaire of own design	Level of knowledge and at- titudes towards people with epilepsy
Marszał et al., 2003	762 students of Silesian schools, from junior secondary school from rural and urban areas, aged 13–15	Questionnaire of own design	Level of knowledge and at- titudes towards people with epilepsy
Talarska et al., 2014	187 employees of service and trading companies aged 20–60	Questionnaire of own design based on Bekiroğlu et al., 2004 and going literature	Level of knowledge and at- titudes towards employees with epilepsy
Doughty et al., 2003	Multicenter study from 10 countries in Europe, among patients with epilepsy aged over 16 and their carers	Compliance with medication, The Impact of Epilepsy Ques- tionnaire, Adjustment to Epi- lepsy scale, The Epilepsy Stigma scale, The Epilepsy Knowledge Questionnaire	Medical aspects, level of knowledge, influence on life, stigma
Novotna and Rektor, 2002	235 persons studied from 1997 to 1998, aged over 16, awaiting dentist's visit at Medical University in Brno	Questionnaire used for the first time in 1949 in the USA, and adopted by Rektor et al., in 1981	Level of knowledge and at- titudes towards people with epilepsy
Mecarelli et al., 2007	344 students of high schools and 253 from university	3-part questionnaire of own design	Level of knowledge and at- titudes towards people with epilepsy
Mecarelli et al., 2010	1556 respondents aged over 18. General social study in Italy	Telephone interview based on 3-part questionnaire of own design	Level of knowledge and at- titudes towards people with epilepsy
Spatt et al., 2005	2.128 adult citizens of Austria, aged over 14	Questionnaire used for the first time in the USA and FRG, adopted in the study of Cavaness and Gallup	Level of knowledge and at- titudes towards people with epilepsy
Jacoby et al., 2004	1694 respondents from Great Britain, aged over 16	Face to face interviews. Research tool – questionnaire of own design	Level of knowledge and at- titudes towards people with epilepsy
Hills and MacKenzie, 2002	400 persons from New Zealand, aged over 17	Face to face interviews. Research tool – 3-part question- naire of own design	Level of knowledge and at- titudes towards people with epilepsy

Table 1. Continued

Authors	Studied group	Tools	Research area
Ok Bozkaya et al., 2010	851 students, aged 11–16, in Turkey. Double study, before and after training	25-item questionnaire of own design based on literature review, i.a. studies in Denmark	Level of knowledge and at- titudes towards people with epilepsy
Bekiroğlu et al., 2004	284 teachers of primary schools in Turkey. Double study, before and after training	4-part questionnaire of own design with 29 questions	Level of knowledge and at- titudes towards people with epilepsy
Kobau and Price, 2003	4397 citizens of United States of various origin, aged over 18	9-question questionnaire HealthStyles, 2002	Level of knowledge and attitudes towards people with epilepsy
Austin et al., 2002	19.441 students aged 13–18 in the USA	37–item questionnaire	Level of knowledge and attitudes towards people with epilepsy
Bishop and Boag, 2006	512 teachers of primary and secondary schools in the USA	ATPE-Scale of Attitudes Toward Persons with Epilepsy	Level of knowledge and at- titudes towards people with epilepsy
Young et al., 2002	Students of College in London, Ontario, Canada	3-part questionnaire: demo- graphic data, knowledge, attitudes	Level of knowledge and at- titudes towards people with epilepsy
Dantas et al., 2001	Teachers of middle school, high and college school from Brazil	11-question questionnaire	Level of knowledge and at- titudes towards people with epilepsy
Otoom et al., 2006	16.044 citizens of Jordan, aged 18–85	Questionnaire with socio-de- mographic part and 5 questions on knowledge about epilepsy	Level of knowledge about epilepsy
Ab Rahman, 2005	289 students in Malaysia, aged 19–39	Questionnaire designed basing on the literature review	Level of knowledge about epilepsy
Kankirawatana, 1999	284 teachers from schools of all levels in Thailand	14-question questionnaire	Level of knowledge and at- titudes towards people with epilepsy
Shafiq et al., 2007	487 adults (over 16) from slum area of Karachi, Pakistan	Questionnaire designed by last year students of medical university	Level of knowledge and attitudes towards people with epilepsy
Pandian et al., 2006	1213 students of 10th grade from Kerala, India	24-question questionnaire	Level of knowledge and at- titudes towards people with epilepsy
Choi-Kwon et al., 2004	1000 persons participating in the study from 25 prefectures in South Korea	23-question questionnaire, made of 3 parts: familiarity with epilepsy (3 items), knowledge (14 items), attitude (6 items)	Level of knowledge and at- titudes towards people with epilepsy
Shehata and Mahran, 2010	189 teachers of secondary school in Assiut City, Egypt	12-question questionnaire	Level of knowledge and at- titudes towards people with epilepsy
Njamnshi et al., 2010	659 students of secondary school in Kumbo, Cameroon	12-question questionnaire	Level of knowledge and at- titudes towards people with epilepsy
Birbeck et al., 2006	171 teachers in Zambia	46-item questionnaire	Level of knowledge and at- titudes towards people with epilepsy
Millogo and Siranyan, 2004	260 teachers from state and private schools in Bobo-Dioulasso, Burkina Faso	19-question questionnaire of own design	Level of knowledge and at- titudes towards people with epilepsy

the group of people with higher education level. Negative influence of the disease on professional activity was observed by 78% of patients, 67% on relations with a partner and 44% with friends. In the knowledge measure questionnaire carers got similar level of 22 points.

The following articles serve as an example of studies investigating the level of knowledge about epilepsy among healthy teenagers and adults: Siemiński et al., 2002; Marszał et al., 2003; Kłos et al., 2005; Zielińska et al., 2006; Talarska et al., 2014. The majority of these publications refer not only to the assessment of the level of knowledge, but they also study attitudes.

The knowledge of factors triggering a seizure was confirmed by 27% of high school teenagers (Kłos et al., 2005) and 29% of junior secondary school students (Zielińska et al., 2006) and almost 57% among teachers (Zielińska et al., 2009). In the study of Siemiński et al. (2002) 24.5% of the studied teenagers agreed with supernatural aetiology of epilepsy. In the same study 95.1% of students believed that children with epilepsy can frequent school together with their healthy peers, in the study of Kłos et al. (2005) it was 71.3% of high school students and 90.7% of teachers (Zielińska et al., 2009). Out of the studied group, 84% of respondents expressed their willingness to make friends with a peer with epilepsy (Kłos et al., 2005). Only 12.3% would be afraid to work with a person with epilepsy (Siemiński et al., 2002). Correct answers concerning proceedings during a seizure were given slightly more often by teenagers who knew people with epilepsy. Both, teachers (71.3%) and teenagers (64.7%) would react incorrectly during a seizure, i.e. they would put an object between jaws (Siemiński et al., 2002; Zielińska et al., 2009). The majority of information about the disorder was acquired by respondents from TV. In the study of Siemiński et al. (2002) 86% of the group believed that people with epilepsy should inform employers and coworkers that they have the disorder. Almost four fifths of the teachers were convinced that epilepsy can be an obstacle when applying for work in some professions. Zielińska et al. (2009) reported a statistically significant association between knowing someone with epilepsy and knowing the factors triggering a seizure, symptoms accompanying a seizure, proper behaviour during a seizure and participation of children in physical education classes.

Marszał et al. (2003) also conducted a study among junior secondary school students. Only 10% of the studied group knew what to do during a seizure. Regarding factors that trigger a seizure, they included: alcohol (70%), going to bed late (50%), discotheque lights (40%), working at the computer (28%). The majority of information was obtained by teenagers from the media. The possibility of attending school by children with epilepsy along with their healthy peers was confirmed by 90% of the group, however 44% did not accept their participation in physical education classes.

Talarska et al. (2014) conducted a study among employees of service and trade companies. Over a half (58%) of respondents declared accepting attitude towards people with epilepsy. Positive answers about employing people with epilepsy were given by 46% of the group. The majority of respondents (88%) wanted patients to inform employers and coworkers about their disorder but only 63% would themselves admit to have it, in case they were ill, in the work place. Over 56% of the group expressed their desire to learn more about epilepsy, especially when it comes to first aid.

Other European countries

Analysis of publications from different countries show that over time knowledge of epilepsy and tolerance towards people with epilepsy has grown. A good example is that of a study undertaken in the Czech Republic (Novotna and Rektor, 2002). Comparing 1981 with that of 1997/98 knowledge about the specifics of the disorder among respondents grew from 78% to 94%. However, 30% of respondents still thought epilepsy was a mental illness. Intolerance towards patients significantly decreased from 29% to 13%. For over 55% of respondents the main source of information about epilepsy was the media. Those respondents who were not ready to help during a seizure gave the following reasons: 33% did not have proper knowledge, 15% were afraid to help others, 18% were afraid that they were not properly prepared, 3% had doubts whether they would be able to tell between an epileptic seizure and an alcoholic attack.

Italy

Mecarelli et al. (2007) conducted in 2005 studies among teenagers of high schools and university students and in 2009 general social studies on people aged over 18 (Mecarelli et al., 2010). 93.4% of adults, 88% of high school teenagers and 96% of university students admitted to knowing about epilepsy. The aetiology of the disorder was unknown to 50.4% of general social study participants and 33% of teenagers. Study partic-

ipants most often gave, as aetiology factors, a head injury and a genetic factor, whereas teenagers and students - a genetic factor and stress. For 4.1% of people in the general social study, epilepsy was considered to be the reason for possession (being possessed by an evil spirit). The knowledge of first aid during a seizure was confirmed by 36.9% of the studied group. Additionally, respondents (general social study/teenagers) thought that epilepsy limited: possibility to acquire a driving license (79.8%/23%), develop a military career (71.1/55%), get regular employment (57.0%/56%), get married (46.2/12%) and procreate (38.7%). Authors showed that there is a correlation of the level of knowledge and attitudes of adult society with an education level, age and sex. Younger persons and women were more critical in respect to marriage, having children and they associated the disorder with the possibility to be possessed.

Austria

In Austria 2,128 adult citizens took part in the research (Spatt et al., 2005). Knowledge of the disease was declared by 89% of the group. Epilepsy was seen as a mental illness by 11% of respondents, 29% did not know the aetiology. In the entire studied group only 10% of respondents showed negative attitudes towards people with epilepsy. The majority of participants (80%) were convinced that children with epilepsy could take up school together with their healthy peers, 11% believed they should frequent special schools. Sex had influence on the knowledge level and attitudes towards people with epilepsy. Women spoke more positively only about marriage of their children with persons with epilepsy. The youngest (14–18) and oldest (> 70) age groups showed more often negative attitudes. People with higher education had higher level of knowledge and acceptance of marriages with a person with epilepsy.

Great Britain

In the research conducted in Great Britain, scientists made an attempt to assess knowledge and social attitudes towards people with epilepsy (Jacoby et al., 2004). It was shown that the majority of people associated an epileptic seizure with a general tonic-clonic seizure. Almost a half of respondents believed that epilepsy is a consequence of a nervous system diseases, a brain disease or a birth defect. When it comes to the assessment of a professional activity they thought that patients should not work as: a soldier (57%), a police of-

ficer (46%), a fire fighter (72%), a truck driver (87%), a factory worker (33%), a nurse (28%), a teacher (20%) or a a shop assistant (6%). When compared to healthy people, 71% of the group thought that people with epilepsy were equally intelligent, 61% that they could be equally successful, 73% that they could play will healthy children. Statistical analysis showed more positive attitudes and a higher knowledge level in: women, people who had a patient with epilepsy in their family, middleaged people and with a higher level of education. The lowest level of knowledge was found in teenagers and young people aged 16–24.

Turkey

The study looked at teenagers before and after an educational program (Ok Bozkaya et al., 2010). Before the training, 49.9% heard or read about epilepsy. 49.1% associated epilepsy with some supernatural illness before and 39.6% after the training. Before the program teenagers more often gave 'food' as a factor triggering a seizure and 'a short sleep' after the training. Less teenagers (30.1%) believed that the head should be protected during first aid before the program and more (54.2%) after it, whereas 19.1% before believed that something should be put between jaws and 36.4% of the group after. A necessity to call for help was reported by 43.7% before and 50.9% after the program.

Another example of a good training outcome was presented by Bekiroğlu et al. (2004), this time teachers of primary schools from Istanbul participated. Before the training 69.3% of the group heard or read about epilepsy, 59.4% knew a person with epilepsy. Out of the group 17.8% believed epilepsy to be a mental illness before the training and 7.0% after it. The biggest changes were observed in the way first aid was delivered. Before the training 41.3% knew how to do it during a seizure and after the training 97.9%. The number of people who would offer an onion or Eau de Cologne to smell dropped from 19.7% to 1.2%. After the training, 77.4% of participants would marry a person with epilepsy in comparison to 59.1% before the seminar. However, less people would agree for their children to marry a person with epilepsy, a change from 24.4% to 26.2%. 86.3% of the group would offer employment to a person with epilepsy before and 97.7% after the training. A statistically significant correlation was found with the majority of answers before and after the training. Statistically significant correlation was also found between majority of answers in the test before and after the training

and sex taken into account. Women overall gave more positive answers than did men.

Australia and Oceania

New Zealand

A study by Hills and Mckenzie (2002) has investigated the knowledge and attitudes of New Zealand residents towards people with epilepsy. Almost the entire group (96%) had heard about epilepsy and only 1% of respondents believed that epilepsy was a form of insanity. Knowledge of possible causes of epilepsy was confirmed by 68% of the group. 91% did not oppose starting up a family with people with epilepsy. However, 69% thought there should not be equal chances in employing people with epilepsy. 60% of the group had knowledge about pharmacological treatment of epilepsy. More women than men spoke positively about their children getting married with a person with epilepsy and about equality when employing people with epilepsy. Among elder people (over 60) the most negative answers were about the possibility that their children may marry a person with epilepsy and the fewest about employing a person with epilepsy.

The studied group showed substantial knowledge about epilepsy.

North and South America

USA

Some of the biggest studies that were conducted in the USA include, Austin et al., (2002), Kobau and Price (2003), Bishop and Boag (2006).

The study carried out in 2002 (Kobau and Price, 2003) focused on knowledge among persons aged over 18. About one third of the group knew someone with epilepsy, almost the same number knew what to do during a seizure and about a half of the group witnessed a seizure. The most often source of information was the media: TV or the Internet. Statistically significant correlation was found between the level of knowledge and age, sex and education. Women showed better knowledge than men. Persons aged 18-24 and over 65 had a low level of knowledge about epilepsy. The main conclusion that the authors drew was that there was a low level of knowledge about epilepsy among society members. Widely available information does not increase the level of knowledge about epilepsy and first aid. Hence, according to authors, educational campaigns should be created to increase the knowledge and built positive attitudes towards people with epilepsy.

The work of Bishop and Boag (2006) in a way completes the above mentioned study. The authors measured the level of knowledge and attitudes towards people with epilepsy among teachers from primary and secondary schools. Also in the study of Austin et al. (2002) - teenagers aged 13-18 were investigated and the mean age of the teachers was 42.8 and had a seniority 15.97 years. More than a half had rarely had contact with people with epilepsy. Among students, only 21% of the group knew someone with epilepsy. A low level of knowledge about epilepsy was reported by 70% of teachers and 67% of students, most of all they did not feel that they were prepared adequately to administer first aid. Epilepsy as a mental illness was perceived by 19% of students (Austin et al., 2002). Almost a half believed that persons with epilepsy can have a driving license and that they can frequent school together with their healthy peers. About 70% of students expressed willingness to make friends with their peers with epilepsy. As to a professional career - 42% of the group spoke positively on the professional activity of people with epilepsy. Only 5% of students had lessons about epilepsy. The main source of information about the disorder for teachers were brochures (44%), websites (30%) and meetings with specialists (31%) (Bishop and Boag, 2006). Over 90% of the teachers were willing to increase their knowledge about the disorder.

The level of knowledge about epilepsy was influenced by the level of education, currently teaching children with epilepsy and contact with the patients. Positive attitudes of the teachers were connected with their bigger professional experience, higher education, female sex, currently teaching children with epilepsy and knowledge about epilepsy.

Canada

The research was conducted among students of psychology and technical disciplines (Young et al., 2002). Students showed a good level of knowledge. Only 9% of students linked epilepsy with a mental illness. Students who knew a person with epilepsy had greater knowledge of the disease. Positive attitudes were shown by 90% of the group. Out of the group 95% accepted getting married with a person with epilepsy. Against having children by people with epilepsy was 11%, and 14% of the students did not wish to employ a person with epilepsy.

Women considerably more often declared positive attitudes towards people with epilepsy.

Brazil

Teachers of three education levels were included in the study: middle school, high school and college (Dantas et al., 2001). Almost all teachers read or heard about epilepsy. About 87% knew a person with epilepsy and about 85% had witnessed a seizure. Some teachers believed that epilepsy is a contagious disease. A few (7% from middle school and 5% from high school) opposed participation of a child with epilepsy in their classes. The majority of teachers thought that people with epilepsy are discriminated after they admit to be ill. A similar percentage thought that students with epilepsy had an intelligence level as that of healthy students. Only one third of the teacher group from the middle school and 50% from college knew what to do during a seizure. About 4.0% of teachers would put an object between jaws during a seizure. The authors concluded that it was a necessity to increase clinical knowledge and also about first aid among teachers.

Asia

In the social study in *Jordan* the mean age was 26.69 (Otoom et al., 2006). Over 80% of the group had over 12 years of education. In the sector connected with health worked, 38.7% responded. Over 70% believed that people with epilepsy should be treated by neurologists but 25.4% also suggested a hypnotherapist, and 22.6% a religious healer. 7.6% said that people with epilepsy can be treated with herbal medication. According to 82.6% of the group, the most important action during a seizure is to protect the head and 26.4% would place an object between jaws. 45.8% confirmed the possibility to give water to drink during a postictal phase. Only 23.4% was convinced that medications positively influence the condition of patients.

Authors showed a relationship between the level of knowledge and age, sex, the level of education and occupation in the studied group. More correct answers were given by women, middle-aged persons (40–59) and those with higher education.

A similar scope of data in studies from *Thailand* (Kankirawatana, 1999), *Malaysia* (Ab Rahman, 2005), *India* (Pandian et al., 2006), *Pakistan* (Shafiq et al., 2007) and *South Korea* (Choi-Kwon et al., 2004) enables to compare the results directly. In *Malaysia* 86.5% of students heard or read about epilepsy and 55.6% of the group had witnessed a seizure (Ab Rahman, 2005). In *Thailand* only 38.0% of teachers read or heard about epilepsy. From the mass media (TV, magazines) information

was gained by 38.7% of respondents (Kankirawatana, 1999). In *Pakistan* 87.5% of people heard about epilepsy (Shafiq et al., 2007). The majority learned about the disorder from friends (80.5%), some from the press – 11.7% and from TV 9.4%. In *India*, 98% of students heard or read about epilepsy (Pandian et al., 2006) and in *South Korea* about 92% (Choi-Kwon et al., 2004). An epileptic seizure was observed by 63.9% of persons. The majority (78.3%) learned about the disorder from other people.

Only one third of the group in Malaysia knew about the aetiology of epilepsy (Ab Rahman, 2005). Epilepsy as contagious disease was recognized by 4.9% of the group and 5.3% believed the cause was evil spirits. In Thailand (Kankirawatana, 1999) among the disorder causes teachers gave injury (17.7%) and infections (15.0%). Epilepsy as a form of insanity was described by 18.0% of the group and as being possessed by 0.9%. In Pakistan epilepsy as a contagious disease was described by 34% of respondents (Shafiq et al., 2007). In India half of the group thought that epilepsy was a brain disorder. 34,1% believed the disorder was of a hereditary background, and 13.9% that it was contagious. In South Korea almost a half of the group believed that epilepsy was a hereditary disorder, one third that it was a brain disorder. As a mental illness epilepsy was taken by 5.1% of the group. Supernatural character was seen in this disorder by 3% of the group (Choi-Kwon et al., 2004).

In *Thailand* about 86% of the study participants did not know how to deliver first aid. 73% would place an object in the mouth during a seizure (Kankirawatana, 1999). Students in India, while performing first aid, would take a patient to hospital (62.4%), 24% would spray the face with water and 7.5% thought that during a seizure a person should be holding keys (Pandian et al., 2006).

In *Malaysia* 46.3% thought epilepsy was a curable disorder (Ab Rahman, 2005), in *Pakistan* over a half (54.2%) believed that antiepileptic drugs were the best form of treatment but 33.1% would choose religious methods (Shafiq et al., 2007). In *India* over a half (59%) of students believed it could be treated with Ayurvedic approach and 55% with allopathic, one fifth saw the success of the treatment also in exorcisms (Pandian et al., 2006). The best place of treatment according to respondents in *South Korea* was hospital (Choi-Kwon et al., 2004).

When analyzing attitudes towards a student with epilepsy, it has been found that 60% of respondents in *Malaysia* thought that epilepsy was not an embarrassing disorder and 70% that patients should not hide that

they are ill. Also over a half of the group (60%) did not see any contraindications to participate in the physical education classes (Ab Rahman, 2005). In *Thailand* 9.8% of teachers were afraid to have a student with epilepsy in their class. Almost all (94.7%) teachers would agree that their children should play with a child with epilepsy and 41.2% that they got married (Kankirawatana, 1999).

Based on conducted statistical analysis in *Pakistan* the following relationships were detected: educated men more often heard about epilepsy, a person who learned about epilepsy from health service or from TV more often believed that epilepsy was curable and antiepileptic drugs effective. Persons who were not educated nor had knowledge about epilepsy nor witnessed an epileptic seizure thought that people with epilepsy, including those on medications, should be isolated from healthy individuals. They more often believed that epilepsy was a contagious disorder and that patients could not continue their academic education. Men had better knowledge than women (Shafiq et al., 2007).

Almost a half (45%) of Indian students that participated in the study thought that society discriminated against a person with epilepsy. One third was convinced that epilepsy was an obstacle to find employment. Additionally, 13% of students would unwillingly sit in the classroom next to a child with epilepsy. Based on the statistical analysis authors concluded, that girls more often than boys were acquainted with a person with epilepsy. Muslims were more often convinced, compared with Hindus, that the cause of the disorder were sins of ancestors (Pandian et al., 2006).

In South Korea, 81,9% agreed that children with epilepsy should play with healthy children and 37.8% agreed that their child could marry a person with epilepsy. 87.4% would work with a person with epilepsy but only 37.5% would employ such a person. After having analyzed the outcomes statistically, the authors concluded that older persons with a lower knowledge level preferred alternative treatment methods and herbal doctors. Persons with negative attitudes towards marriage and having children by people with epilepsy believed that epilepsy was hereditary and incurable. Persons who were against employing people with epilepsy did not believe much in the success of the treatment (Choi-Kwon et al., 2004).

Africa

Four publications containing information that enabled

comparison of data have been reviewed (Millogo and Siranyan, 2004; Birbeck et al., 2006; Shehata and Mahran, 2010; Njamnshi et al., 2010).

In these publications the studied groups, apart from students in *Cameroon*, were teachers. In *Egypt* 100% of respondents knew or heard about epilepsy, 98% in Bobo-Dioulasso (*Burkina Faso*), 95.6% in *Zambia* and 94.7% in *Cameroon*.

In Cameroon brain diseases were believed to be the main cause of the disorder (18.5%), followed by mental illnesses (14.3%) and heredity (12.4). Students who believed that epilepsy was a contagious disease gave as a possible source: waste gas (27.5%), saliva (14.1%) and blood (7.0%) (Njamnshi et al., 2010). In Egypt 10.2% of teachers believed that epilepsy was a form of mental illness (Shehata and Mahran, 2010). In Zambia respondents gave as a main cause of the disorder: a brain injury (71.6%) and spirit possession 20% (Birbeck et al., 2006). Out of all teachers in the study, in Bobo-Dioulasso (Burkina Faso) 43.2% believed epilepsy was a central nervous system disease, 11.9% a contagious disease and 30.7% a madness. 40.0% of the group had first aid knowledge. Almost four fifths of the group stated that during a seizure would remove dangerous objects and secure the head. 27.5% of respondents would place an object between jaws (Millogo and Siranyan, 2004). In Cameroon during a seizure 41.6% of students would place an object in the mouth and 1.1% would give their own blood to drink (Njamnshi et al., 2010). Two thirds of the group recommended treatment advised by a doctor but 30% suggested a traditional healer and asking for help from God.

In *Zambia* four fifths of teachers thought that treatment should be advised by a doctor but over one third that it should be a traditional healer or a church healing session (Birbeck et al., 2006).

Factors influencing attitudes of students in *Cameroon* were: the belief that epilepsy is a contagious disease or some form of a mental illness, witnessing a seizure, female sex, Christian denomination and a higher education level (Njamnshi et al., 2010).

In *Egypt* only 1.1% of the group confirmed negative perception of students with epilepsy. 14.3% of the teachers thought that students with epilepsy had greater problems because of mental changes (Shehata and Mahran, 2010). A place of education for students with epilepsy, according to 45.5% of the teachers, should be a school with healthy students and for 4.8% a special school.

In Zambia teachers showed positive attitudes (Birbeck et al., 2006). 96.6% would agree that their children could play with children with epilepsy, 75.8% believed that children were equally intelligent as healthy children. 44.2% of respondents, agreed that their children could marry a person with epilepsy. Statistical analysis showed that people who knew persons with epilepsy or saw a seizure were more tolerant.

In Bobo-Dioulasso (*Burkina Faso*) epilepsy as a discrimination reason was noted by 73.1% of the group though, 81.2% of teachers believed that children with epilepsy were equally intelligent as healthy individuals (Millogo and Siranyan, 2004).

The majority of teachers would like to get information about first aid and aetiology as well as disorder specifics during a training (Birbeck et al., 2006, Millogo and Siranyan, 2004).

DISCUSSION AND CONCLUSION

Analysis of the reviewed publications show that the knowledge about the disorder specifics, including factors triggering a seizure and first aid, is low, also in respondents from well developed countries (Kankirawatana, 1999; Austin et al., 2002; Millogo and Siranyan, 2004; Ab Rahman, 2005; Zielińska et al., 2006). The use of various research instruments and vague answers hinder clear summary of the literature review. For example, some articles include only general questions: 'Do respondents know how to provide first aid?' or 'Do they know the factors triggering the disease or a seizure?' and authors do not verify this information or only do not explain in the publication whether the respondents did have such knowledge (Kankirawatana, 1999; Kobau and Price, 2003; Ab Rahman, 2005; Pandian et al., 2006; Mecarelli et al., 2010; Njamnshi et al., 2010).

Although not all articles give a clear answer to the question: how many people know proper first aid during a seizure?, in the majority of publications respondents chose wrong methods. The biggest problem in most publications was a conviction that during a seizure an object should be placed between jaws.

Another example showing a low level of knowledge about the disorder can be the fact that epilepsy was associated by some respondents with supernatural powers (Ab Rahman, 2005; Pandian et al., 2006; Birbeck et al., 2006; Mecarelli et al., 2010). These people very often, reported traditional healing methods as being almost as good as pharmacological treatment. This view was particularly dominant among developing countries

(Ab Rahman, 2005; Birbeck et al., 2006; Pandian et al., 2006, Njamnshi et al., 2010).

According to some authors (Buck et al., 1999; Doughty et al., 2003; Jacoby et al., 2004; Zielińska et al., 2006; Talarska et al., 2014) the way long-term ill persons are perceived (in this case with epilepsy) is largely conditioned by the level of knowledge a person has and the fact of knowing a person with epilepsy (Kobau and Price, 2003; Jacoby et al., 2004; Bishop and Boag, 2006; Otoom et al., 2006; Pandian et al., 2006; Birbeck et al., 2006; Njamnshi et al., 2010). The issue of perceiving a patient is of crucial significance when it comes to shaping the attitudes of society. This in turn influences the quality of life of people with epilepsy and how open they will be to participate in social life (Buck et al., 1999; Dantas et al., 2001; Young et al., 2002; Morrell, 2002; Choi-Kwon et al., 2004; Millogo and Siranyan, 2004; Birbeck et al., 2006; Zielińska et al., 2006; Pandian et al. 2006; Shafiq et al., 2007; Shehata and Mahran, 2010; Njamnshi et al., 2010; Mecarelli et al., 2010). Despite the quite low level of knowledge in the majority of countries respondents showed a high level of acceptance.

A lower tolerance level was only revealed by questions about marriage with a person with epilepsy, having children or employing patients (Kankirawatana, 1999; Hills and MacKenzie, 2002; Pandian et al., 2006; Mecarelli et al., 2007). Though, in some publications (Jacoby et al., 2004; Mecarelli et al., 2007; Mecarelli et al., 2010) authors stress that perceiving limitations in employment, as seen by respondents, may stem from regulations in force in a given country. Thus epilepsy can be a contraindication to employ in a specific position. Another reason was the lack of belief in the success of the treatment (Choi-Kwon et al., 2004). Respondents who opposed having children by persons with epilepsy were most of all those who gave heredity as a possible factor causing the disorder (Choi-Kwon et al., 2004) and older people (over 60). Older respondents with lower knowledge more often reported negative attitudes towards getting married or having children (Hills and Mckenzie, 2002; Kobau and Price, 2003; Spatt et al., 2005).

Respondents from *Poland* showed lower level of knowledge and noticed more limitations in employing people with epilepsy when compared to other studies' participants conducted in Europe. However, in the context of all the analyzed publications, they did not differ significantly in the level of knowledge or declared attitudes.

Some respondents already during a study signaled their willingness to participate in the training about the disorder specifics and first aid (Kobau and Price, 2003; Millogo and Siranyan, 2004; Birbeck et al., 2006). Positive influence of education was shown by authors of the study conducted in the Czech Republic (Novotna and Rektor, 2002) and Turkey (Bekiroğlu et al., 2004; Ok Bozkaya et al., 2010). To increase the level of knowledge among students Zielińska et al., (2006) proposed an educational lesson plan for teachers. May and Pfäfflin (2002) assessed the effectiveness of the program Modular Service Package Epilepsy (MOSES) among people with epilepsy. After a short, 2-day training, its participants were satisfied with the program and demonstrated improvement in dealing with their own condition.

The above described observations support the necessity to design educational programs both, among patients and students who will constitute a base for the general social knowledge.

Described background reveals an important role of teachers who, as shown by the literature review, often lack the necessary knowledge themselves (Kankirawatana, 1999; Millogo and Siranyan, 2004; Birbeck et al., 2006; Zielińska et al., 2009; Shehata and Mahran, 2010). Thus, there should be trainings for this group of workers as well.

The channel for public education that should be used is the media, particularly TV, as it was many times the only source of information about epilepsy in the various studied societies.

CONFLICT OF INTEREST DISCLOSURE

The authors have no conflict of interest to declare.

REFERENCES

2002, 3: 368-375.

Ab Rahman A.F.: Awareness and knowledge of epilepsy among students in Malaysian university. Seizure, 2005, 14: 593–596. Austin J.K., Osborne Shafer P., Beach Deering J.: Epilepsy familiarity, knowledge, and perceptions of sigma: report from a survey of adolescents in general population. Epilepsy Behav.,

Baker G.A., Brooks J., Buck D., Jacoby A.: *The Sigma of Epilepsy: A European Perspective*. Epilepsia, 1999, 41: 98–104. Bekiroğlu N., Ózkan R., Gürses C., Arpaci B., Dervent A.:

A study on awareness and attitude of teachers on epilepsy in Istanbul. Seizure, 2004, 13: 517–522.

Birbeck G.L., Chomba E., Atadzhanov M., Mbewe E., Haworth A.: Zambian teachers: What do they know about epi-

lepsy and how can we work with them to decrease stigma? Epilepsy Behav., 2006, 9: 275–280.

Bishop M., Boag E.M.: Teachers' knowledge about epilepsy and attitudes toward students with epilepsy: results of a national survey. Epilepsy Behav., 2006, 8: 397–405.

Buck D., Jacoby A., Baker G.A., Lye H., Steen N.: Cross-cultural differences in health-related quality of life of people with epilepsy: findings from a European study. Qual. Life Res., 1999, 8: 675–685.

Choi-Kwon S., Park K.A., Lee H.J., Park M.S., Lee C.H., Cheon S.E. et al.: Familiarity with, knowledge of, and attitudes toward epilepsy in residents of Seoul, South Korea. Acta Neurol. Scand., 2004, 110: 39–45.

Dantas F.G., Carii G.A., Carii G.A., Vaz Riberio Fiho A.R.: Knowledge and attitudes toward epilepsy among primary, secondary and tertiary level teachers. Arq. Neuropsiquiatr., 2001, 59: 712–716.

de Boer H.M., Mula M., Sander J.W.: The global burden and sigma of epilepsy. Epilepsy Behav., 2008, 12: 540–546.

Doughty J., Baker G.A., Jackoby A., Lavaud V.: *Cross-cultur-al Differences in Levels of Knowledge about Epilepsy*. Epilepsia, 2003, 44: 115–123.

Fernandes P.T., Salgado P.C.B., Noronha A.L.A., Barbosa F.D., Souza E.A.P., Li M. Li: Stigma Scale of Epilepsy: Conceptual Issues. J. Epilepsy Clin. Neurophysiol., 2004, 10: 213–218. Hills M.D., Mackenzie H.C.: New Zealand Community Attitudes toward People with Epilepsy. Epilepsia, 2002, 43: 1583–1589.

Jacoby A., Gorry J., Gamble C., Baker G.A.: Public Knowledge, Private Grief: A Study of Public Attitudes to Epilepsy in the United Kingdom and Implications for Stigma. Epilepsia, 2004, 45: 1405–1415.

Jacoby A.: *Epilepsy and Stigma: An Update and Critical Rewiev.* Curr. Neurol. Neurosc. Reports, 2008, 8: 339–344.

Kankirawatana P.: Epilepsy Awareness Among School Teachers in Thailand. Epilepsia, 1999, 40: 497–501.

Kłos E., Talarska D., Zielińska A.: Padaczka – wiedza młodzieży licealnej. Neurol. Dziec., 2005, 13, Supll: U-29.

Kobau R., Price P.: Knowledge of Epilepsy and Familiarity with This Disorder in the U.S. Population: Results from the 2002 Health Styles Survey. Epilepsia, 2003, 44: 1449–1454.

Majkowski J., Dobrzyńska L., Artemowicz B., Kmieć T., Nowak S., Owczarek K.: Charakterystyka demograficzno-społeczna i zdrowotna 6024 chorych z padaczką w Polsce od VI 2000 do V 2001. (Demographic, Social and Medical Characteristics of 6204 Epileptic Patients in Poland in 2000–2001. Multicenter Prospective Study. Wieloośrodkowe badania prospektywne). Epileptologia, 2003, 11: 101–119.

Majkowski J., Majkowska-Zwolińska B.: Cechy demograficz-

ne, społeczne i medyczne 1019 chorych z padaczką. Prospektywne, wieloośrodkowe badania kosztów padaczki w 2006 r. w Polsce. (Demographic, Social and Medical Characteristics of 1019 Epileptic Patients. A Prospective, Multi-centre Study of the Costs of Epilepsy in Poland in 2006). Epileptologia, 2007, 15: 119–139.

Marszał E., Emich-Widera E., Klimek B., Boczarska M., Cieliński Ł., Śmiłowski M. et al.: Stan wiedzy na temat padaczki oraz postawy wobec osób dotkniętych tym schorzeniem. Neurol. Dziec., 2003, 12: 41–44.

May T.W., Pfäfflin M.: The Efficacy of an Educational Treatment Program for Patients with Epilepsy (MOSES): Results of a Controlled, Randomized Study. Epilepsia, 2002, 43: 539–549. Mecarelli O., Li Voti P., Vanacore N., D'Arcangelo S., Mingoia M., Pulitano P. et al.: A questionnaire study on knowledge of and attitudes toward epilepsy in schoolchildren and university students in Rome, Italy. Seizure, 2007, 16: 313–319.

Mecarelli O., Capovilla G., Romeo A., Rubboli G., Tinuper P., Beghi E.: Past and present public knowledge and attitudes toward epilepsy in Italy. Epilepsy Behav., 2010, 18: 110–115.

Millogo A., Siranyan A.S.: Knowledge of epilepsy and attitudes towards the condition among schoolteachers in Bobo-Dioulasso (Burkina Faso). Epileptic. Disord., 2004, 6: 21–26.

Morrell M.J.: *Stigma and epilepsy*. Epilepsy Behav., 2002, 3: S21-S25.

Niedzielska K., Wolańczyk T., Baker G. A., Jakoby A., Dughty J., De Boer H.: Poziom wiedzy na temat padaczki wśród polskich pacjentów i ich rodzin w badaniu europejskim SPOKE (2004). Neurol. Neurochir. Pol., 2004, 38: 447–455.

Njamnshi A.K., Tabah E.N., Zoung-Kanyi Bissek A.C., Yepnjio F.N., Kuate C., Angwafor S.A. et al.: *Knowledge, attitudes and practice with respect to epilepsy among secondary school students in the Kumbo West Health District – North West Region – Cameroon.* Epilepsy Behav., 2010, 18: 247–253.

Novotna I., Rektor I.: The trend in public attitudes in the Czech Republic towards persons with epilepsy. Eur. J. Neurol., 2002, 19: 535–540.

Otoom S.A., Al.-Safi S.A., Sequeira R.P., Alkofahi A.S.: Knowledge of management of epilepsy in young adults in Jordan. Epilepsy Behav., 2006, 9: 349–354.

Ok Bozkaya I., Arhan E., Serdaroglu A., Soysal A.S., Ozkan

S., Gucuyener K.: Knowledge of perception of attitudes toward epilepsy of schoolchildren in Ankara and the effect of an educational program. Epilepsy Behav., 2010, 17: 56–63.

Pandian J.D., Santosh D., Kumar T.S., Sarma P.S., Radhakrishnan K.: High school students' knowledge, attitude, and practice with respect to epilepsy in Kerala, southern India. Epilepsy Behav., 2006, 9: 492–497.

Sander J.W.: *The epidemiology of epilepsy revisited*. Curr. Opin. Neurol., 2003, 16: 165–170.

Shafiq M., Tanwir M., Tariq A., Kasi P.M., Zafar M., Saleem A. et al.: Epilepsy: Public knowledge and attitude in a slum area of Karachi, Pakistan. Seizure, 2007, 16: 330–337.

Shehata G.A., Mahran D.G.: Knowledge, attitude and practice with respect to epilepsy among school teachers in Assiut city, Egypt. Epilepsy Res., 2010, 92: 191–200.

Siemiński M., Nyka W.M., Kudelska K., Batko E.: Ocena poziomu wiedzy na temat padaczki i stosunku do tej choroby wśród młodzieży 18-letniej, uczącej się w gdańskich liceach ogólnokształcących. (Assessment of knowledge of epilepsy and attitudes towards the disease among 18-year-old students of secondary schools in Gdańsk). Epileptologia, 2002, 10: 333–343. Spatt J., Bauer G., Baumgartner Ch., Feucht M., Graf M., Mamoli B. et al.: Predictors for Negative Attitudes toward Subjects with Epilepsy: A Representative Survey in the General Public in

Talarska D., Witkowska M., Michalak M.: Attitudes of employees of service and trading companies towards people with epilepsy and their professional activity in Poland. Seizure, 2014, 23: 178–183.

Austria. Epilepsia, 2005, 46: 736-742.

Young G.B., Derry P., Hutchinson I., John V., Matijevic S., Parrent L. et al.: An Epilepsy Questionnaire Study of Knowledge and Attitudes in Canadian College Students. Epilepsia, 2002, 43: 652–658.

Zielińska A., Talarska D., Kłos E., Michalak M.: *Grammar School Youth's Attitudes Towards Epileptics*. Annales Universitatis Meriae Curie-Skłodowska Lublin, Polonia sectio D, 2006, LX Suppl XVI: 456–459.

Zielińska A., Talarska D., Zendlewicz-Morysiak A.: Na-uczyciel jako edukator młodzieży na temat padaczki. (Teacher as an educator of adolescents about epilepsy). Epileptologia, 2009, 17: 173–182.