

Knowledge and attitudes towards epilepsy among inhabitants of Silesia.

A questionnaire study

Wiedza i postawy wobec padaczki wśród mieszkańców województwa śląskiego.

Badanie ankietowe

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Abstract

Background and purpose: Epilepsy is one of the most frequent neurological diseases. Social acceptance is very important for people with epilepsy and their relatives. The aim of the study was to assess public knowledge and attitudes towards epilepsy in Silesia.

Material and methods: We examined 419 people, inhabitants of Silesia, at the mean age of 34 ± 15 years. The study was performed using a questionnaire containing 15 questions evaluating knowledge about epilepsy and attitudes towards people with epilepsy.

Results: 43.2% of the respondents knew an epileptic person themselves. 44.7% had witnessed an epileptic seizure; 68.8% would help a person during an epileptic seizure, but most of them (73.4%) would do it incorrectly (by putting an object into the mouth to prevent biting the tongue). 94.5% of respondents had nothing against friendship with an epileptic person, but 12.1% suggested that children with epilepsy should attend special schools. 85.9% of all those examined said that people with epilepsy should inform others about their disease, 81.9% would mention the existence of an epileptic person in their family. 40.5% of respondents believe that people with epilepsy can do the same jobs as healthy people, 75.3% would employ an epileptic person themselves.

Streszczenie

Wstęp i cel pracy: Padaczka to jedna z najczęstszych przewlekłych chorób układu nerwowego. Społeczna akceptacja jest bardzo ważna dla osób chorujących na padaczkę i ich rodzin. Celem pracy była ocena wiedzy na temat padaczki oraz postaw wobec osób nią dotkniętych wśród mieszkańców województwa śląskiego.

Materiał i metody: W badaniu wzięło udział 419 mieszkańców województwa śląskiego, w średnim wieku 34 ± 15 lat. Zastosowano kwestionariusz składający się z 15 pytań dotyczących wiedzy i postaw wobec padaczki.

Wyniki: Spośród ankietowanych 43,5% stwierdziło, że zna lub znała osobę chorującą na padaczkę. 44,7% badanych była wcześniej świadkiem napadu padaczkowego. Większość (68,8%) deklarowała chęć udzielenia pomocy w trakcie napadu, lecz aż 73,4% uczyniłoby to niewłaściwie (poprzez włożenie jakiegoś przedmiotu między zęby osoby chorej). Aż 94,5% ankietowanych nie miałoby nic przeciwko temu, aby w grupie przyjaciół znalazła się osoba chora na padaczkę, a 12,1% uważało, że dzieci chore na padaczkę powinny chodzić do specjalnych szkół. 85,9% badanych twierdziło, że osoby chore na padaczkę powinny informować otoczenie o swojej chorobie, nieco mniej (81,9%) powiedziałoby innym, gdyby w rodzinie była osoba chora. 40,5% ankietowanych jest zdania, że chorujący na padaczkę mogą pracować.

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Conclusions: The knowledge about epilepsy and first aid during epileptic seizure is still insufficient among inhabitants of Silesia. Most of the responders, especially better educated ones, declare acceptance and tolerance of people with epilepsy. More effort should be made to improve public knowledge of epilepsy by preparing wide-spread educational programmes.

Key words: epilepsy, knowledge, attitudes, questionnaire.

Introduction

Epilepsy is one of the most common chronic neurological disorders. About 400 000 people with epilepsy live in Poland, and the incidence is 40-70 per 100 000 per year. Despite such prevalence and despite constant increase in knowledge and availability of effective medications, patients with epilepsy are often underprivileged [1-4]. This situation decreases their quality of life and remains a source of suffering not infrequently greater than the seizures themselves. Social acceptance is very important for patients with epilepsy and their families. It is related, however, to reliable knowledge about epilepsy among lay people.

Recent literature contains many reports on the social attitude towards patients with epilepsy, which suggests great interest in this problem [5-17]. Polish studies on the knowledge and attitude towards epilepsy sufferers were performed and published mostly in the 1970s [18-21]. Recent studies are few, involve small groups of participants and usually consider selected social groups [22-29].

The aim of the study was to assess public knowledge on epilepsy and attitudes towards people with epilepsy in Silesia, Poland.

Material and methods

This study used an anonymous questionnaire containing 15 closed questions related to epilepsy and evaluating attitudes towards patients with epilepsy. The questionnaire was prepared by the authors with the use of available literature [5,8,9,11,14-16].

The study was performed between October and December, 2008 in one chosen day of the week in ran-

wać w tych samych zawodach co osoby zdrowe, aż 70,5% zatrudniłoby taką osobę osobiście.

Wnioski: Wiedza na temat padaczki oraz znajomość zasad udzielania pierwszej pomocy osobie w trakcie napadu padaczkowego jest wciąż niedostateczna wśród mieszkańców Śląska. Większość badanych, zwłaszcza lepiej wykształconych, deklaruje postawę akceptacji oraz tolerancji wobec osób chorujących na padaczkę. Istnieje potrzeba przygotowania i rozpowszechnienia programu edukacyjnego, który zawierałby podstawowe informacje na temat choroby i postępowania z osobą chorą w trakcie napadu.

Słowa kluczowe: padaczka, wiedza, postawy, kwestionariusz.

domly selected offices of family physicians in the cities of the Silesian agglomeration. Participants were all subjects who visited a family physician on that day and agreed to participate. None of those subjects suffered from epilepsy. A total of 419 people were surveyed, which is almost 0.01% of all inhabitants of the Silesian Voivodship. The number of surveyed people was related to the time devoted to the interview. The face-to-face method was employed to obtain answers to questions included in the questionnaire.

The inclusion criterion was a positive answer to the question 'Have you ever heard or read about epilepsy?'. A positive answer was provided by 398 subjects (95%) and their questionnaires were subsequently analysed. Statistical analysis was performed with Statistica 6.0 PL; Mann-Whitney *U*-test and Spearman correlation coefficient were used.

Results

The study group consisted of 398 subjects at the mean age of 34 ± 15 years (range 15-85), including 194 women (mean age 36 ± 16 years) and 204 men (mean age 32 ± 15 years). The majority of patients received secondary education (Fig. 1).

Almost half of the participants (43.2%) declared that they knew somebody who had epilepsy; women responded positively more often than men (48.5% vs. 38.2%).

Nearly half of the subjects (44.7%) stated that they had witnessed an epileptic seizure; women positively answered that question more often than men (50% vs. 39.7%). More than two-thirds of those who had witnessed an epileptic seizures (69%) knew somebody with epilepsy.

The vast majority of respondents (94.5%) did not object to making friends with a person suffering from epilepsy.

Twelve percent of participants thought that children with epilepsy should attend special schools.

Nearly three-quarters (68.8%) of respondents were willing to help somebody who experienced an epileptic seizure. The major reasons for not helping were lack of knowledge (66.1%), fear (15.2%), and a combination of those two reasons (11.9%). The majority of respondents stated that placing an object in the mouth of the patient during a seizure was always appropriate and indicated. Almost three-quarters of those subjects (73.4%) previously declared willingness to help in such a situation.

One question was related to the possible causes of epilepsy. Respondents could choose more than one suggested answer. Most participants indicated brain disease or brain trauma (93.3%), more than a half thought that epilepsy might result from alcohol abuse (59.8%) or perinatal injury (59.2%). More than 23% of respondents thought that epilepsy was mental disease, 15.6% combined epilepsy with heart disease, and 15.8% could not point to any cause of epilepsy. A few subjects (1%) stated that epilepsy was a contagious disease, and 35.2% indicated inheritance as a cause of epilepsy.

Another question concerned provocative factors. Respondents most often mentioned alcohol (84.9%), disco lights (71%), and sleepless night (57.1%). Computer work (47.9%), and an inappropriate diet (38.1%) were suggested less often.

The vast majority of participants (85.9%) thought that people with epilepsy should inform people they know about the disease. Less often (81.9%), they would tell their friends about the disease affecting themselves or their family member. These people constituted 91.1% of people who stated that the social circle of the patient should be informed of his/her epilepsy.

Most respondents (75.3%) declared that the presence of epilepsy did not affect their decision on the possible employment of such a person, but only 40.5% of participants thought that people with epilepsy might be employed in the same jobs as healthy ones.

Answers to most questions are reported in Table 1.

We also analysed the association between respondents' level of education and answers to particular questions. Answers to some questions (no. 4, 5, 6, 14, 15) differed significantly in relation to the level of education. Those better educated rarely objected to having a person with epilepsy among their friends, and rarely

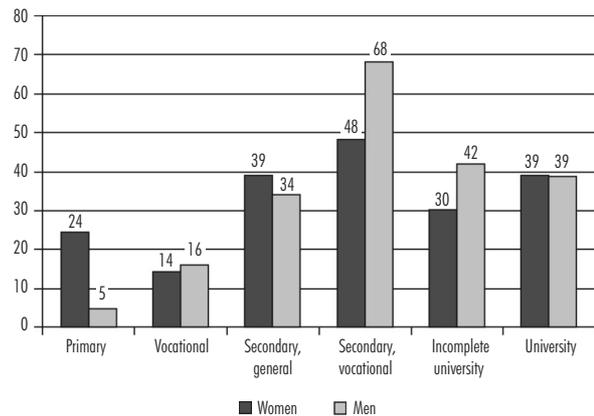


Fig. 1. Education level of study participants

suggested that children with epilepsy should attend special schools. Subjects with a university degree more often declared willingness to help somebody during an epileptic seizure. Level of education also affected the attitude towards employment of patients with epilepsy – better educated respondents would employ somebody with epilepsy more willingly, although they knew that not all jobs were suitable for people with epilepsy.

No significant correlation was found between knowledge of epilepsy and the place of residence (all respondents lived in towns) or present occupation.

Discussion

The term 'epilepsy' is derived from the Greek verb *epilambanein*, which means 'to attack', 'to be embraced', 'to seize'. Epilepsy was known in ancient times and was mentioned by Hippocrates in 'Corpus Hippocraticum' as a distinct entity. Epilepsy has always aroused interest, but those affected were usually discriminated against by others.

According to the results of our study among inhabitants of Silesia, the disease is almost universally known. Almost all respondents (95%) declared that they had heard or read about epilepsy. This result is similar to those reported in the 1970s and 1980s and suggests common and constant functioning of the term 'epilepsy' in public awareness [18-21].

Nearly half of the participants (44.7%) had witnessed an epileptic seizure. A similar percentage of respondents (43.2%) declared that they knew somebody suffering from epilepsy. These findings are consistent with other studies performed in Poland and in other European countries during the last decade [14,25,30,31] but percent-

Table 1. Responses to some questions of the questionnaires

Question	All participants N = 398	Women N = 194	Men N = 204	p-value
Do you know or have you ever known anyone who has/had epilepsy?				
Yes	172 (43.2%)	94 (48.5%)	78 (38.2%)	< 0.05
No	226 (56.8%)	100 (51.5%)	126 (61.8%)	< 0.05
Have you ever witnessed an epileptic seizure?				
Yes	178 (44.7%)	97 (50%)	81 (39.7%)	< 0.05
No	220 (55.3%)	97 (50%)	123 (60.3%)	< 0.05
Would you ever object to a person with epilepsy being among your friends?				
Yes	22 (5.5%)	12 (6.2%)	10 (4.9%)	NS
No	376 (94.5%)	182 (93.8%)	194 (95.1%)	NS
Do you think that children with epilepsy should attend special schools?				
Yes	48 (12.1%)	18 (9.3%)	30 (14.7%)	< 0.05
No	350 (87.9%)	176 (90.7%)	174 (85.3%)	< 0.05
Would you help someone who experienced an epileptic seizure?				
Yes	274 (68.8%)	136 (70.1%)	138 (67.6%)	NS
No	120 (31.2%)	58 (29.9%)	66 (32.4%)	NS
Do you think that placing an object in the mouth of a person experiencing an epileptic seizure is an appropriate action?				
Yes	308 (77.4%)	152 (78.4%)	156 (76.5%)	NS
No	90 (22.6%)	42 (21.6%)	48 (23.5%)	NS
Do you think epilepsy is a contagious disease?				
Yes	4 (1%)	2 (1%)	2 (1%)	NS
No	394 (99%)	192 (99%)	202 (99%)	NS
Do you think epilepsy is a hereditary disease?				
Yes	140 (35.2%)	69 (35.6%)	71 (34.8%)	NS
No	258 (64.8%)	125 (64.4%)	133 (65.2%)	NS
Do you think that people with epilepsy should inform people they know about the disease?				
Yes	342 (85.9%)	167 (86.1%)	175 (85.5%)	NS
No	56 (14.1%)	27 (13.9%)	29 (14.5%)	NS
Would you tell your friends if you or anyone in your family suffered from epilepsy?				
Yes	326 (81.9%)	164 (84.5%)	162 (79.4%)	< 0.05
No	72 (18.1%)	30 (15.5%)	42 (20.6%)	< 0.05
Do you think that people with epilepsy should be employed in the same jobs as healthy people?				
Yes	161 (40.5%)	86 (44.3%)	75 (36.8%)	< 0.05
No	237 (59.5%)	108 (55.7%)	129 (63.2%)	< 0.05
Would you employ a person with epilepsy, if you were an employer?				
Yes	300 (75.3%)	146 (75.3%)	154 (75.5%)	NS
No	98 (24.7%)	48 (24.7%)	50 (24.5%)	NS

ages are clearly lower than in Polish studies performed 30 years ago [20] and in reports from developing countries [12,15,16]. This probably results from the more effective treatment of epilepsy in Poland (better seizure control due to the use of newer antiepileptic drugs, greater awareness of the disease among affected people), and therefore easier hiding of the disorder by the sufferers.

Despite common awareness of the disease, the majority of lay people still have no working knowledge of the appropriate action to take when witnessing an epileptic seizure. Almost three-quarters of those surveyed declared willingness to help somebody during an epileptic seizure but the vast majority would do that inappropriately (more than 70% of respondents stated that placing an object into the mouth of the patient during a seizure is always correct and indicated). Our adverse results are similar to those obtained in other Polish studies. Among studied pupils of primary schools [22], as many as 80% of respondents voted for placing an object in the mouth of the patient during an epileptic seizure. Klimek *et al.* [23] reported that 81% gave a response indicating inappropriate intervention. Siemiński *et al.* [24] found that only 35% of secondary school students knew how to intervene appropriately. Similar results were also obtained in PRO-EPI, an opinion poll performed by the Pentor Institute at the request of the Polish Society of Epileptology and UCB pharmaceutical company between February and March 2009 [29]. The study concerned social aspects of epilepsy and included 1042 adult Polish participants, 179 neurologists who took care of patients with epilepsy, 1019 adults suffering from epilepsy, 313 parents of children with epilepsy, and 200 headmasters of primary and secondary schools. Forty-three percent of surveyed adult participants declared having working knowledge of the appropriate first aid during an epileptic seizure, but 84% of them would insert something hard into the mouth of a person experiencing an epileptic seizure. According to the current rules of first aid, in the case of an epileptic seizure this is not indicated because of the usual jaw spasms; this manoeuvre might result in breaking of teeth or other injury. An appropriate reaction includes protection of the patient (especially his/her head) against potential injury, placing the patient in a safe position after the seizure and close observation, or calling emergency services in the case of a prolonged seizure.

Answers to questions related to general knowledge on epilepsy were equivocal. Only 15% of respondents could not choose any cause of the disease, and most of

the remaining 85% chose appropriate causes (brain disease, brain trauma, alcohol abuse, perinatal injury). On the other hand, more than 20% of respondents thought that epilepsy was a mental disorder, and 15% associated epilepsy with heart disease. The results of other studies in Poland were similar – epilepsy was considered as a mental disease by 13% of respondents in the PRO-EPI study.

Increased tolerance for people with epilepsy may be a cause for optimism. Acceptance is shown in the answers to questions on attitudes towards patients with epilepsy. Study participants, especially better educated ones, present themselves as being quite tolerant towards the disease. The vast majority of subjects declare no objections to becoming friends with a person suffering from epilepsy, and only 10% of respondents thought that children with epilepsy should attend special schools.

Some limitations related to the questionnaire-based studies should be taken into account. Closed questions may result in random, hasty answers. Thus, it is sometimes difficult to clearly interpret the answers. In general, we may infer some trends related to the knowledge and attitude towards affected people and the disease itself. It is worth noting that the attitude towards the disease is influenced not only by knowledge but also by personal experience.

According to the PRO-EPI study, as many as 40% of children with epilepsy attend special schools, integrating institutions or have individual learning plans. Children suffering from epilepsy are reluctantly admitted to normal schools due to teachers' inadequate knowledge of epilepsy and due to the fear of seizures occurring during classes [32].

It seems that concerns related to social rejection and discrimination are less intense nowadays – only 1/5 of those surveyed would conceal the information about epilepsy from their close relatives and would not inform their friends.

The issue of employment of chronically ill epileptic patients and tolerance in the workplace are major problems. We found that three-quarters of respondents would employ a person with epilepsy. According to the PRO-EPI study, about 48% of patients with epilepsy are employed. The situation improved greatly in relation to the previous decade. The SPOKE study performed in 2000 in several European countries assessed the knowledge of epilepsy among patients with epilepsy and their relatives [10]. The study revealed that only 24% of Polish patients with epilepsy were employed, while in other countries (e.g. Netherlands, United King-

dom) the corresponding rate was about 50% [33]. Almost 80% of participants stated that their disease significantly affected their work.

According to our questionnaire study performed among inhabitants of Silesia (Poland), acceptance and tolerance for people with epilepsy seems to be greater than previously. On the other hand, the knowledge of the disease and ability to provide first aid in the case of witnessing a seizure is still inadequate. It is necessary to develop a special educational programme and implement it in the general population.

Conclusions

1. Knowledge about epilepsy and first aid during epileptic seizures is still insufficient among inhabitants of Silesia.
2. Most of the respondents, especially better educated ones, declare acceptance and tolerance for people with epilepsy.
3. More effort should be made to improve public knowledge of epilepsy by preparing widespread educational programmes.

Disclosure

Authors report no conflict of interest.

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Appendix

Questionnaire related to knowledge on epilepsy and attitudes towards people with epilepsy (*The original version is in Polish*)

Age: years **Sex:** woman man

Education level:

Incomplete primary	<input type="checkbox"/>	Secondary, general	<input type="checkbox"/>
Primary	<input type="checkbox"/>	Incomplete university	<input type="checkbox"/>
Vocational	<input type="checkbox"/>	University	<input type="checkbox"/>
Secondary, vocational	<input type="checkbox"/>		

Present occupation:.....

Place of residence:.....

1. Have you ever heard or read about the disease called 'epilepsy'?
 YES NO
2. Do you know or have you ever known anyone who has/had epilepsy?
 YES NO
3. Have you ever witnessed an epileptic seizure?
 YES NO
4. Would you ever object to a person with epilepsy being among your friends?
 YES NO
5. Do you think that children with epilepsy should attend special schools?
 YES NO
6. Would you help someone who experienced an epileptic seizure?
 YES NO
- If 'NO', why?
 - a) because of lack of knowledge
 - b) because of fear
 - c) due to other reasons
7. Do you think that placing objects in the mouth of the person experiencing an epileptic seizure is an appropriate action?
 YES NO
8. What do you think causes epilepsy?
 - a) heart disease YES NO
 - b) brain disease or brain trauma YES NO
 - c) perinatal injury YES NO
 - d) mental disease YES NO
 - e) alcohol abuse YES NO
 - f) I don't know
9. Do you think epilepsy is a contagious disease?
 YES NO
10. Do you think epilepsy is a hereditary disease?
 YES NO
11. Seizures in patients with epilepsy may be provoked by:
 - a) alcohol YES NO
 - b) disco lights YES NO
 - c) working with computer YES NO
 - d) sleepless night YES NO
 - e) inappropriate diet YES NO
12. Do you think that people with epilepsy should inform people they know about the disease?
 YES NO
13. Would you tell your friends if you or anyone in your family suffered from epilepsy?
 YES NO
14. Do you think that people with epilepsy should be employed in the same jobs as healthy people?
 YES NO
15. Would you employ a person with epilepsy, if you were an employer?
 YES NO