

Knowledge about Epilepsy among Patients under Community Care

Wiedza na temat padaczki wśród pacjentów objętych opieką środowiskową

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Abstract

Introduction. Insufficient knowledge and misconception about epilepsy causes the development of negative attitudes towards epilepsy patients, increases stigmatization and psychosocial problems, and consequently affects their quality of life.

Aim. The aim of the study was to assess the state of knowledge of primary care patients on epilepsy.

Material and Methods. The study included a group of 149 patients from three primary health care facilities in the city of Bydgoszcz. The study population consisted of 99 women (66%) and 50 men (34%). Adults predominated, the mean age of the respondents was 43.91 years (SD=13.03). The research used the method of diagnostic survey, the research tool was the original questionnaire. The research was carried out in a correlation model. The non-parametric Spearman rank test was used to determine the significance of the relationship between demographic variables and knowledge about epilepsy. The significance level $p < 0.05$ was considered statistically significant.

Results. The vast majority of respondents (97%) have heard about epilepsy in their lives and believe that they have knowledge about this disease (90%) and know the main cause (76%). Moreover, most of the respondents (96%, 97%) know that during an attack, the patient should be safely positioned and their head protected against injuries. Unfortunately, only 47% of the respondents were ready to help the sick.

Conclusions. Most of the respondents have heard about epilepsy in their lifetime and believe they have knowledge of epilepsy. More than half of the respondents witnessed an epileptic seizure. Readiness to provide first aid during an epileptic seizure is declared by nearly half of the respondents. The vast majority of respondents accept people with epilepsy in the work environment as well as in the social environment. There is a relationship between gender, age and education, and some aspects of knowledge about epilepsy and the presented opinion about the disease. (JNNN 2021;10(3):105–111)

Key Words: epilepsy, knowledge, patient

Streszczenie

Wstęp. Niedostateczna wiedza i błędne wyobrażenie na temat padaczki powoduje rozwój negatywnych postaw wobec pacjentów z padaczką, zwiększa stygmatyzację i problemy psychospołeczne, a w konsekwencji wpływa na ich jakość życia.

Cel. Celem przeprowadzonych badań było dokonanie oceny stanu wiedzy pacjentów Podstawowej Opieki Zdrowotnej na temat padaczki.

Materiał i metody. Badaniem objęto grupę 149 pacjentów trzech placówek świadczących Podstawową Opiekę Zdrowotną na terenie miasta Bydgoszczy. Badaną populację stanowiło 99 kobiet (66%) oraz 50 mężczyzn (34%). Przeważały osoby dorosłe, średni wiek respondentów wynosił 43,91 lat (SD=13,03). W badaniach zastosowano metodę sondażu diagnostycznego, narzędziem badawczym był autorski kwestionariusz ankiety. Badania zostały przeprowadzone w modelu korelacyjnym. Do określenia istotności związku pomiędzy zmiennymi demograficznymi a wiedzą o padaczce wykorzystano test nieparametryczny rang Spearmana. Za istotny statystycznie przyjęto poziom istotności $p < 0,05$.

Wyniki. Zdecydowana większość badanych (97%) słyszała w swoim życiu o epilepsji i uważa, że posiada wiedzę na temat tej choroby (90%), a także zna główną jej przyczynę (76%). Ponadto większość badanych (96%, 97%) wie, że podczas ataku należy zapewnić choremu bezpieczne ułożenie oraz zabezpieczyć jego głowę przed urazami. Niestety gotowość udzielenia pomocy choremu wyraziło zaledwie 47% respondentów.

Wnioski. Większość badanych słyszała w swoim życiu o epilepsji i uważa, że posiada wiedzę na temat tej choroby. Ponad połowa respondentów była świadkami napadu padaczkowego. Gotowość do udzielenia pierwszej pomocy podczas napadu padaczkowego deklaruje blisko połowa ankietowanych. Zdecydowana większość badanych akceptuje osoby z padaczką w środowisku pracy, jak również w środowisku społecznym. Istnieje związek pomiędzy płcią, wiekiem i wykształceniem a niektórymi aspektami wiedzy na temat padaczki oraz prezentowaną opinią na temat tej choroby. (PNN 2021;10(3):105–111)

Słowa kluczowe: padaczka, wiedza, pacjent

Introduction

Epilepsy is one of the most common neurological disorders among humanity and is associated with stigma and discrimination [1]. It is a chronic neurological disease that is often associated with supernatural activities in society. The presentation of such observations by people is mainly due to the lack of knowledge and awareness about epilepsy. There are beliefs that the outbreak of epilepsy is an unnatural or supernatural activity [2]. Insufficient knowledge and misconception about epilepsy causes the development of negative attitudes towards epilepsy patients, increases stigmatization and psychosocial problems, and consequently affects the quality of life of these people [3]. According to the WHO, epilepsy is a chronic brain disorder that affects people of all ages. About 50 million people with epilepsy have been diagnosed worldwide, making it one of the most common neurological diseases worldwide. Almost 80% of patients live in underdeveloped and middle-developed countries, and therefore about 25% of people do not receive the necessary treatment. WHO also draws attention to the stigma and discrimination surrounding this disease [4].

The aim of the study was to assess the state of knowledge of Primary Health Care patients on epilepsy. The study drew attention to the presented attitude of the respondents to people with epilepsy and the experiences related to this disease. Moreover, the impact of selected socio-demographic factors (gender, age, education, marital status, professional activity) on the level of knowledge about epilepsy was assessed.

Material and Methods

Study Population

The study included a group of 149 people — patients of three primary health care facilities in the city of Bydgoszcz. The study population consisted of 99 women (66%) and 50 men (34%). Adults predominated, the

mean age of the respondents was 43.91 years (SD=13.03). The youngest respondent was 18 years old and the oldest was 86 years old. All respondents lived in the city. The study group was characterized using the following data: gender, education, marital status, professional activity (Table 1).

Table 1. Characteristics of the study group

Variable	N	%
Gender		
Women	99	66
Men	50	34
Age		
Young	6	4.03
Adult	114	76.24
Senior	29	19.46
Education		
Primary	5	3.36
Vocational	37	24.83
Secondary	60	40.27
Higher	47	31.54
Marital status		
Single	30	20.13
Married	93	62.42
Widow/widower	15	10.07
Divorced	11	7.38
Professional activity		
White-collar worker	69	46.31
Manual worker	41	27.52
Pensioner	18	12.08
Retiree	11	7.38
Unemployed	4	2.64
Student	6	4.03

Research Procedure and Research Tool

The full survey procedure consisted in filling in only the self-questionnaire. The survey was voluntary and anonymous. Conducting this research project posed no risk to the respondents.

The research used the diagnostic survey method, and the research tool was the original questionnaire. It was constructed independently on the basis of the available literature and the QOLIE-31 quality of life questionnaire with epilepsy [5–8]. At the beginning of the questionnaire, a birth certificate was placed, containing the personal data of the respondents: age, gender, education, marital status, professional activity. Further on, the questionnaire contained questions related to the knowledge of epilepsy and the acceptance of epilepsy patients in the social and professional environment. The issues included in the questionnaire were divided into 4 parts and contained information on the knowledge, knowledge of people suffering from epilepsy, patient acceptance and available sources of information about epilepsy. To obtain information on the knowledge about epilepsy among patients, only those questions from the questionnaire where there was a statistically significant difference between the analysed variables were selected.

The statistical analysis was performed using the statistical program Statistica 8.0. The research was carried out in correlation model. Spearman's non-parametric rank test was used to determine the significance of the relationship between demographic variables and knowledge about epilepsy. The significance level of $p < 0.05$ was adopted as statistically significant.

Results

The vast majority of respondents, i.e. 97%, have heard about epilepsy in their life and believe that they have knowledge about this disease (90%) and know its main cause (brain damage — 76%). Approx 46% of respondents believe that epilepsy mainly affects young people, and only 9% of respondents believe that people over 65 years of age. 70% of respondents can name the symptoms of an epileptic seizure. The highest percentage of respondents indicated convulsions as the main symptom of epilepsy (89%) and loss of consciousness (77%). Among the surveyed, 68 people (46%) did not witness an epileptic seizure, while 81 respondents (54%) witnessed such an incident. Most of the respondents, i.e. 96–97% know that during an attack, the patient should be positioned safely, away from objects which he could hit and that his head should be protected against injuries. 67% of respondents had contact with epilepsy and did not reveal their fear of these patients. Despite the fact that the respondents had contact with epilepsy, there are few people suffering from epilepsy in the circle of their friends — 29%. Most of the respondents, i.e. 93%, accept the sick at work and do not think that they are less effective employees. Moreover, 83% of respondents would employ a person suffering from epilepsy in their company. He vast majority of respondents accept people suffering from epilepsy in their community. However, 78% of respondents believe that people with epilepsy should inform the community about their disease. Unfortunately, only 47% of the respondents were ready to help the patient (Table 2).

Table 2. Respondents' knowledge about epilepsy

Variable	Yes		No	
	N	%	N	%
1	2	3	4	5
Respondent's knowledge about epilepsy:				
1. Have you ever heard. The largest percentage about epilepsy?	145	97	4	3
2. Do you know what epilepsy is?	134	90	15	10
3. Who is affected by epilepsy?				
a. Children	35	23.65	–	–
b. Young people	68	45.95	–	–
c. People over 65	13	8.78	–	–
d. Other	32	21.62	–	–
4. Can you name the symptom of epilepsy?	102	70	44	30
5. Can seizures be a symptom of epilepsy?	133	89	16	11
6. Could loss of consciousness be a symptom of epilepsy?	114	77	35	23
7. Did the respondents witness an epileptic seizure?	81	54	68	46
8. Do you know how to behave during an attack?	90	61	58	39
9. Is it necessary to safely position the patient during an epilepsy attack?	144	97	5	3

Table 2. Continued

	1	2	3	4	5
Respondents' experiences with epilepsy:					
1. Have you met an epileptic person?		98	67	49	33
Acceptance of patients with epilepsy at work:					
1. Would you hire a person with epilepsy?		124	83	25	17
2. Can a person suffering from epilepsy actively participate in professional life?		138	93	11	7
3. Is the person suffering from epilepsy less active?		35	24	113	76
Acceptance of patients with epilepsy in society:					
1. Can people with epilepsy actively participate in social life?		138	93	11	7
2. Should a person suffering from epilepsy inform about their disease?		115	78	32	22
3. Would you be able to help a sick person?		69	47	79	53

The vast majority of respondents (92%) believe that too little is said about epilepsy in the mass media. About 23% of respondents learned about epilepsy from television, more than 5% from the Internet, and only 12% obtained such knowledge in a clinic.

There is a statistically significant relationship between gender and some aspects of knowledge about epilepsy. On the basis of the applied Spearman rank test, it was found that there are significant correlations between

some of the questions. Positive with a question about the effectiveness of work of a person suffering from epilepsy. This means that men are more likely to answer this question in the affirmative, and women in the negative ($p=0.026$; $R=0.183$). Negative with a question regarding, among others, knowledge about first aid, employment of a person suffering from epilepsy and others. This proves that women are more likely to answer this question in the affirmative and men in the negative (Table 3).

Table 3. Sex relationship with knowledge about epilepsy

Variable pairs	N	R	T(N-2)	Level p
Gender & Have you ever heard of epilepsy?	149	-0.234	-2.91	0.004
Gender & Have you ever witnessed a seizure?	145	-0.205	-2.54	0.012
Gender & Would you know how to behave during a seizure?	148	-0.171	-2.09	0.038
Gender & Should the patient be safely positioned during an epilepsy attack?	149	-0.183	-2.26	0.025
Gender & Have you ever met someone with epilepsy?	147	-0.235	-2.91	0.004
Gender & If you were an employer, would you hire someone with epilepsy?	149	-0.213	-2.65	0.009
Gender & Do you think that a person with epilepsy can actively participate in working life?	149	-0.234	-2.92	0.004
Gender & Is the person with epilepsy a less effective worker?	148	0.183	2.25	0.026
Gender & Can people with epilepsy actively participate in social life?	149	-0.234	-2.92	0.004
Gender & Is your knowledge so great that you could help a person without hesitation during an epileptic attack?	148	-0.168	-2.06	0.041

There is also a statistically significant relationship between age and some aspects of knowledge about epilepsy. Positive with questions:

1. Does he know what epilepsy is? ($p=0.043$);
2. Should people with epilepsy inform the community about their disease? ($p=0.048$).

This means that older people are more likely to answer this question in the affirmative, and younger people — in negative (Table 4).

There is a statistically significant relationship between education and some aspects of knowledge about epilepsy.

Positive with questions:

1. Could he name at least one symptom of a seizure? ($p=0.009$; $R=0.215$);
2. Can he name the symptoms of epilepsy? ($p=0.035$; $R=2.13$);
3. Can body seizures be a symptom of epilepsy? ($p=0.037$; $R=0.171$);
4. Could loss of consciousness be a symptom of epilepsy? ($p=0.017$; $R=0.196$).

Table 4. Relationship of age with knowledge about epilepsy

Variable pairs	N	R	T(N-2)	Level p
Age & Do you know what epilepsy is?	149	0.166	2.04	0.043
Age & Should people with epilepsy inform the community about their disease?	147	0.163	1.99	0.048

Table 5. Relationship between education and knowledge about epilepsy

Variable pairs	N	R	T(N-2)	Level p
Education & Who is more likely to suffer from epilepsy?	148	-0.176	-2.15	0.033
Education & Could you name at least one symptom of a seizure?	146	0.215	2.64	0.009
Education & Can you name the symptoms of epilepsy?	149	0.173	2.13	0.035
Education & Can body seizures be a symptom of epilepsy?	149	0.171	2.10	0.037
Education & Could loss of consciousness be a symptom of epilepsy?	149	0.196	2.42	0.017

This means that people with higher education are more likely to answer this question in the affirmative, and people with lower education — negative.

Negative with the question: Who is more likely to suffer from epilepsy? ($p=0.033$; $R=-0.176$). This means that people with lower education are more likely to answer this question in the affirmative, and people with higher education — negative (Table 5).

Discussion

Knowledge about the essence of epilepsy has a huge impact on the acceptance of patients in the social environment, and thus improves the quality of life of people affected by this disease. Many authors take up this problem in their research, assessing the level of knowledge about epilepsy in various environments, including students, teachers, students of primary schools, middle schools, high schools, city dwellers [9,10].

Our research shows that 97% of the surveyed patients have heard about epilepsy, 90% know what epilepsy is, and 76% of the respondents had knowledge about the aetiology of the individual. Similar results were obtained in the study of Alhazzani et al., where among 1044 people nearly 96.1% had heard about epilepsy. Despite this, the participants lacked knowledge about the aetiology of epilepsy, as 40% considered it as blood disorders, and 21.2% as contagious, and almost 1/3 perceived it as mental and emotional disorders [11]. Also in studies by Macit et al. it was found that the vast majority of participants know epilepsy, but only 18 out of 219 had detailed information about the disease. In turn, nearly 25% of the respondents had knowledge about the aetiology of epilepsy, and most of the respondents knew that epilepsy is not a form of mental illness [1]. Similar results were also obtained in the research conducted by Kaddumukas et al., where nearly 91% of respondents had

heard or read about epilepsy or knew a person suffering from epilepsy. On the other hand, 37% did not know the cause of epilepsy, and about 70% of the respondents believed that epilepsy is an infectious disease [12]. In turn, in the studies of Al-Dossari et al. approximately 95% of the respondents have heard or read about epilepsy. On the other hand, 70% of respondents knew that epilepsy is a neurological disease, and 46.5% of people believed that its main causes are demons and evil spirits [13]. In turn, in the research conducted by Kiwanuka and Anyango, the majority of respondents had a low level of knowledge about epilepsy [14].

In our research on the knowledge of epilepsy symptoms, nearly 70% of respondents could name at least one symptom of an epileptic seizure. The largest number of respondents — 89% knew that seizures are a symptom of epilepsy, while 77% of respondents associated epilepsy with loss of consciousness. Talarska et al. report that in the group of study students from Poznań, seizure symptoms were most often associated with limb tremors (76%), loss of consciousness (44%) and convulsions (30%) [15]. In turn, in a study by Krishnaiah et al., knowledge about the clinical features of a seizure was owned by 25.8% of respondents [16].

In the presented study, 81 people (54%) witnessed an epileptic seizure. Most of the respondents, i.e. 96–97% knew the rules of first aid during an epileptic seizure, while the readiness to provide first aid to a patient during an attack was declared by only 47% of the respondents. 67% of respondents had contact with people suffering from epilepsy. Similar results were obtained in the work of Alhazzani et al., where 60.7% of the respondents also knew people suffering from epilepsy. Moreover, nearly 50% of the respondents did not know the rules of providing first aid [11]. On the other hand, in studies by Almutairi et al. among 706 respondents nearly 51% knew people suffering from epilepsy, and 55.7% witnessed an epileptic seizure. The first aid measures

were the first to be made by the respondents to make a phone call to medical services (49.7%) and to keep the patient away from danger (48.3%) [17]. In studies by Al-Hashemi et al. among teachers, nearly 29.3% met a person suffering from epilepsy. About 35% of respondents claimed that they had the knowledge necessary to provide first aid during a seizure [18]. In turn, in a study by Al-Dossari et al. nearly 63% of respondents knew people suffering from epilepsy, and 49.75% witnessed an epileptic seizure [13]. On the other hand, in a study conducted by Kapinos among medical students, approximately 38.1% met a person suffering from epilepsy, and 38.5% saw an epileptic seizure incident. Half of the respondents indicated that placing an object in the mouth during an epileptic seizure is the correct procedure [19]. In turn, in the studies of Jansen et al. 24% of participants during an epileptic seizure would hold the person lying on the ground, while 19% would also put an object in the mouth of a person during a seizure [20]. On the other hand, in the studies conducted by Al-Harbi et al. [21] among teachers, only 31.8% of them reported readiness to provide first aid during an epileptic attack [21].

In the results obtained by us, nearly 67% of respondents do not disclose their fear of people suffering from epilepsy. Most of the respondents, i.e. 93% accept the sick at work and do not think that they are less effective employees. Moreover, 83% of respondents would employ a person suffering from epilepsy in their company. Moreover, the majority of respondents accept epilepsy patients in their community, and the same number believe that patients with epilepsy may marry and have children. In turn, in studies by Al-Dossari et al., approximately 65% of respondents would allow their offspring to play with people suffering from epilepsy. Interestingly, 59% of respondents would also allow their descendants to marry someone with epilepsy. About 82% agreed to work with people with epilepsy, and 85.5% would easily become their close friends. Almost 53% of respondents believe that people suffering from epilepsy should have equal opportunities to be employed with healthy people [13]. In turn, in the studies by Al-Harbi et al. among teachers, 36.9% believe that students with epilepsy should be treated equally with their healthy peers. On the other hand, 63.1% feel sorry for people suffering from epilepsy. However, approximately 14% of teachers believe that children with epilepsy should attend special schools [21]. In the studies by Guekht et al., almost half of the respondents would not let their child play or learn with a child suffering from epilepsy. On the other hand, 57% of respondents would also object to their child's marriage to a person suffering from this disease [22]. In turn, in the study of Jansen et al., only 3% of high school students would not like to be friends with a person suffering from

epilepsy, while 22% of respondents would not want to go on a date with sick person [20]. In turn, 19.1% of respondents in the study by Alhazzani et al. would not want to work with people with epilepsy, and 17% of them would not allow their child to learn and play with a child suffering from epilepsy. More than half of the respondents would also not decide to marry a person suffering from epilepsy [11].

Our research showed that 92% of respondents believe that too little is said about epilepsy in the mass media. Only 23% of respondents mentioned TV as their source of information, and only 12% found out about epilepsy in the clinic. In a study by Macit et al., pharmacists have been identified as the main source of information on epilepsy [1]. On the other hand, Teferi and Shewangizaw indicated that among the participants of their research, nearly 64.3% had information from the mass media (TV, Radio), while 22.1%, 12.6% and 1.9% of respondents had information from health facilities, health professionals and schools [23]. Similar results were obtained in the work of Al-Hashemi et al., where the percentage of 60.5% of the respondents also obtained information about epilepsy from public media, then from the Internet (41.3%), and during education at school (25.4%), and from health professionals (19.3%) [18].

Conclusions

1. Most of the respondents have heard about epilepsy in their lifetime and believe they have knowledge of the disease and its root cause.
2. More than half of the respondents witnessed as epileptic seizure.
3. Readiness to provide first aid during an epileptic seizure is declared by nearly half of the respondents.
4. Most of the respondents had contact with people suffering from epilepsy, moreover, for the vast majority of respondents, this disease would not prevent them from maintaining closer contacts with these people.
5. Among the vast majority of respondents, people with epilepsy are accepted in the work environment as well as in the social environment.
6. There is a relationship between gender, age and education, and some aspects of knowledge about epilepsy and the opinion presented about it.

Implications for Nursing Practice

Epilepsy is a social disease that causes biopsychological problems in those affected. People with epilepsy require the urgent help of another person during the attack, and then complete acceptance and support in everyday

functioning in all areas of life. Public awareness of epilepsy could contribute to minimizing the problems of people with epilepsy and their complete acceptance. Hence the education of the society should be continued all the time, especially by nurses, starting with education in the school environment. The public visiting primary care clinics should have access to materials presenting first aid in an epilepsy attack and brochures presenting knowledge about epilepsy.

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
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