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Attitudes of professionally active adults towards patients with epilepsy. Pilot study

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SUMMARY

Background. Attitudes are formed throughout the course of our lives, and they result from our knowledge, experience or belonging to a particular group of people. Stereotypes, prejudice, or discrimination are often the consequence of uncritical copying the behaviour of others and the lack of knowledge.

Aim. The aim of the study was to answer the following question: What attitudes towards patients with epilepsy are declared by adults undertaking professional activity?

Materials and Methods. Included in the study were professionally active persons aged between 35 and 60 years. The research tool was our own questionnaire. The questions referred to the three components of the attitude: knowledge, emotions, behaviours.

Results. The study group comprised 58 (58.59%) women and 41 (41.41%) men. The average age was 46.3±10.2 years. Most respondents completed full tertiary education (n=68, 68.69%). The average score obtained by the studied group from the entire questionnaire was 20.3 out of 27 points, which suggests that the investigated group represented positive attitudes. The highest score was obtained by the respondents in the affective component of attitudes, whereas the lowest was recorded in the behavioural

Conclusion. Majority of people participating in the study showed a positive attitude. In the study group, the most difficult questions were those about first aid and direct relations with the patients. Women, respondents with higher education, single and those who do intellectual work have a better perception of people suffering from epilepsy. White-collar workers and women would be more willing to employ and collaborate with a person with epilepsy.

Key words: attitudes • epilepsy • social activity

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BACKGROUND

The attitude is reflected in the tendency to react in a certain way to a given stimulus (Mishra, 2018). This can be an object, an animal or a person, e.g. a person with epilepsy. Moreover, the stimulus is a result of three elements: knowledge, emotions and behaviour. The cognitive component refers to beliefs, the affective component represents the emotions the observed subject evokes, whereas the behavioural component represents our actions performed as a result of the two previous elements.

Attitudes are shaped throughout life. Initially, we are influenced by parents, teachers and a peer group, and in the later periods of life we tend to be influenced by people we meet, e.g. in the workplace, or as a result of shared interests. This process is explained by the theory of social learning, according to which attitudes are formed by imitating the models we choose (Hjerm et al., 2018; Mishra, 2018). In fact, attitudes may correspond to the general social norms or be group-specific (Hjerm et al., 2018). Negative attitudes result from incorrect components, i.e. stereotypes, prejudice and discrimination (Altmann, 2008; Mishra, 2018). The most common cause of prejudice is the uncritical transfer of the characteristics found in the entire group to individuals, without taking into account their individual differences, where the belief whereby all patients suffering from epilepsy have cognitive disorders can constitute an example (Brodie, 2003; Altmann, 2008). People are stigmatized if they present a trait which, in the group's opinion, is badly perceived, such as epileptic seizures (Jacoby et al.,1978). Negative attitudes become stronger when the stigmatised person shares the same beliefs as the individuals evaluating that person (Brodie, 2003). Certain stereotypes still persist today in the group of people with epilepsy and in their families, such as the belief that individuals suffering from epilepsy should not have children or have no professional career development. Unfortunately, such an attitude reinforces low self-esteem and social isolation (Obeid, 2008; WHO, 2010). In fact, people with epilepsy abandon social contact and remain at home for fear of a social reaction to a generalised epileptic seizure (WHO, 2010). This, in turn, contributes to the development of aggression, anxiety and depression (Mlinar et al., 2016; Mishra, 2018).

There are a number of reasons for stigmatising the chronically ill, such as the relatively late introduction of regulations (also in the developed countries) prohibiting discrimination against people with various health disorders and disabilities in public areas, such as admission to school or employment (Obeid, 2008). Discrimination contributes to the withdrawal from social activity of individuals who are not accepted. Such forced isolation is not conducive to confrontation and, thus, to a better understanding of people with particular health disorders, including epilepsy. Research conducted in this area indicates that living with people suffering from epilepsy favours changing attitudes and rejecting the myths associated with this disease (Talarska et al., 2014).

As a chronic disease, epilepsy affects various aspects of human life. One of the areas of importance for patients is the psychosocial sphere. On an individual level, a well-developed social integration means active participation in social life, the development of abilities and an increase in prosperity through employment and, globally, a contribution to the economic development of the country (Mlinar et al., 2016).

Unemployment and under-employment of individuals with epilepsy occurs in many countries, including the highly developed (Brodie, 2003; WHO, 2010). Although the situation of people suffering from epilepsy has been improving, they continue to report difficulties in employment and suffer discrimination in the workplace (Murphy, 2017; Muller-Heyndyk, 2019). One stereotype is that people with epilepsy are more likely to take sick leaves and to have accidents at a workplace. Nevertheless, research in Ireland has demonstrated that the prevalence of these phenomena in healthy people is comparable (Murphy, 2017). Discrimination (stigmatisation) contributes to social exclusion with all its negative consequences and is seen as a determinant of poor social prognosis (Mlinar et al., 2016).

AIM

The aim of the study was to answer the following question: What attitudes towards patients with epilepsy are declared by adults undertaking professional activity?

MATERIAL AND METHODS

Organisation of research

During the period September–October 2020 104 random people aged 35–60, undertaking various professional activities were surveyed. All questionnaires were completed electronically. Due to incomplete questionnaires only 99 were included in the final analysis.

The exclusion criteria included the following factors:

- epilepsy in the respondent or in the immediate family,
- a medical professional.

Research tools

The research tool was an electronic questionnaire, which was developed on the basis of a questionnaire by Bekiroğlu et al. (2003). Simultaneously, the majority of the questions from the questionnaire used in the research in 2013 (Talarska et al., 2014) were included. The questions referred to the three components of the attitude. The questionnaire comprised: 10 questions regarding the knowledge of the disease process, 7 questions pertaining to the affective component, 7 questions concerning the behavioural component and 3 questions referring to the employment of people with epilepsy.

The overall result of the questionnaire is in range of 0 to 27 points. Higher scores reflect a more positive attitude towards people with epilepsy. Generally, a positive attitude represents people who obtained a score above 20 points.

The questionnaire began with 3 testing questions:

- Have you ever heard of epilepsy?
- Do you know anyone suffering from epilepsy?
- Have you seen someone having a seizure?

An important element of the questionnaire was a table containing demographic data including age, gender, education, marital status, residence, presence of a chronically ill person in the immediate family as well as information on professional activity: job seniority, nature of work, position held, the number of co-workers.

Statistical analysis

The qualitative variables, as well as the answers to the questions, are described in terms of number (n) and frequency (%). The measurable variables are described by means of basic parameters: arithmetic mean, standard deviation (deviations), median and minimum and maximum value (min. and max.).

Since the overall result of the questionnaire is a measurable variable described on a scale, non-parametric tests were used for statistical analyses:

- the Mann-Whitney U test to verify the significance of the difference in two groups,
- the Kruskal-Wallis test to assess the significance

- of the difference in at least 3 groups. A post-hoc test was used to verify exactly which pairs of groups present significant differences.
- Spearman's rank correlation coefficient to investigate the correlation between measurable variables.

The value of p < 0.05 was assumed to be statistically significant. Statistical calculations were performed using the statistical package STATISTICA 10 PL.

RESULTS

Research group characteristics

The research group comprised 58 (58.59%) women and 41 (41.41%) men. The average age was 46.3 ± 10.2 years. Most people completed full tertiary education (n = 68, 68.69%) and secondary education (n = 23, 23.23%), whereas only 9 (9.09%) had vocational education.

66.67% (n = 66) of respondents were married. 56.57% (n = 56) of respondents lived in full family (spouses+children), 25.25% (n = 25) additionally with their parents.

A chronically ill person in the closest family was found in 35 (35.35%) respondents.

Statistical analyses showed no significant differences (p>0.05) between men and women following the analysis of the demographic data.

Analysis of the questions from the "Attitudes towards people with epilepsy" questionnaire

In the study group, all respondents (100%) confirmed that they have heard or read about epilepsy, 36 respondents (36.36%) know a person suffering from epilepsy. However, no one had seen a major epileptic seizure.

The average score obtained by the research group from the entire questionnaire (Table 1) was 20.3 (77.8%) out of 27 points and confirms a positive attitude.

The behavioural component referred to the declared behaviours and was evaluated as the weakest of all analysed parts. The fewest positive answers were obtained in questions directly related to the respondents, e.g. only 36 (36.36%) of the respondents would start a family with a person suffering from epilepsy, 50 (50.51%) would agree for their own child to marry a person suffering from epilepsy. However, as many as 90 (91.91%) would agree to the friendship of their child with a person suffering from epilepsy and 93 (93.94%) would spend their free time with the person suffering from epilepsy.

The cognitive component (Table 2) has shown that

Table 1. "Attitudes towards people with epilepsy" questionnaire of

Attitude components	N	Mean	Standard deviation	Median	Min.	Max.	Scope
Cognitive	99	6.0	2.2	6.0	1	10	0-10
Affective	99	6.4	1.0	7.0	3	7	0-7
Behavioural	99	5.3	1.6	5.0	0	7	0–7
Professional	99	2.6	0.7	3.0	0	3	0-3
Results	99	20.3	3.7	21.0	5	26	0-27

Table 2. Cognitive component questions

No.	Question	Correct answers N %	;
1.	Is epilepsy an infectious disease?	99	100.00
2.	Is epilepsy a mental disease?	80	80.81
3.	Do all patients suffering from epilepsy present with the same symptoms?	73	73.74
4.	Is epilepsy treatable?	15	15.15
5.	Can certain seizures end within seconds without anyone noticing?	75	75.76
14.	Do all persons lose consciousness during a seizure?	64	64.65
16.	Does every person with an epileptic seizure need to use an antiepileptic medication?	34	34.34
18.	Do you think it makes sense to hold hands and legs during a seizure?	36	36.36
19.	Do you know how to help a patient with epilepsy during a seizure?	66	66.67
24.	Do you know the factors which may trigger a seizure?	50	51.51

although the studied group has a fairly high level of knowledge (6 out of 7 points on average) about epilepsy, there are areas of knowledge which require improvement.

Despite years of social education, questions regarding first aid in case of a seizure are still most difficult. One third of the group reported that they did not know how to act appropriately during a seizure. Moreover, about 1/3 of the respondents would hold limbs during a seizure. Only half (51.51%) of the research group knew the factors triggering a seizure.

The studied group obtained the best score in questions referring to the affective component.

Respondents gave affirmative answers to questions about the ability of a child with epilepsy to succeed at school, acceptance of getting married, having children and attending social gatherings at the level of 92–98%. Independent living of people suffering from epilepsy was least accepted (68.69%).

The average score obtained by the study group in the questions concerning employment (Table 3) was 2.6 ± 0.7 out of 3 points. The respondents showed most doubts in the question referring to the situation when they were to employ people with epilepsy. A positive answer was given by 75.76% of the group.

Statistical analyses presenting the influence of demo-

graphic and occupational factors on opinions pertaining to people with epilepsy were performed separately for questions related to professional activity (3 questions) and for other statements (24 questions) describing opinions about people suffering from epilepsy (Table 4).

A correlation has been found between age, seniority and number of co-workers and the opinion on people with epilepsy. The opinion of people with epilepsy deteriorated with age and the length of work experience. However, the higher the number of co-workers, the higher the respondents' opinion regarding people with epilepsy. The variables included in the analysis demonstrated a difference in the perception of people with epilepsy with all other demographic and occupational factors. Only the fact that a chronically ill person was present in the family did not discriminate against people suffering from epilepsy. The analysis using the Mann-Whitney test revealed that women, people with higher education, married, and people performing intellectual work presented a better perception of people with epilepsy. In addition, it was found that managers in larger companies expressed better opinions than those who were self-employed.

Similar differences (p < 0.05) were found in the analysis (Kruskala-Wallis test) when taken into account the influence of demographic factors on the opinion on

Table 3. Opinions regarding the employment of people suffering from epilepsy

No.	Question	YES	DON'T KNOW	NO			
		n	%	n	%	n	%
12.	If you were a manager, would you employ a person suffering from epilepsy?	75	75.76	20	20.20	4	4.04
13.	Could a person with epilepsy be your co-worker?	87	87.88	6	6.06	6	6.06
25.	Should people with epilepsy be employed?	95	95.96	4	4.04	0	0.00

Table 4. Opinions pertaining to people with epilepsy vs. demographic and occupational factors

Variable		Average score (max. 24 points)	p-value
Canadan	Woman	18.4±3.6	0.0076 ¹
Gender	Man	16.5 ± 3.5	0.0076
Education .	Higher	18.4 ± 3.4	0.0029 ¹
Education	Secondary and vocational	16.0±3.7	0.0029
Manda I sasass	Single	19.7±2.3	0.0022 ¹
Marital status	Married	17.1 ± 3.7	0.0022
A chronically ill person	Yes	18.4±2.9	0.3259 ¹
in the family	No	17.3 ± 4.0	0.3259
Character of annular manual	Intellectual work	19.00 ± 2.7	< 0.0001 ¹
Character of employment	Physical work	15.0 ± 4.2	< 0.0001
	Manger	20.1 ± 2.2	
Position	Employee	17.9 ± 3.0	0.0428^2
	Self-employed	16.2±4.7	
Age		$r_s = -0.313 \ 0.0050$	
Number of co-workers		$r_s = 0.232 0.0409$	
Seniority		$r_s = -0.266 0.0185$	

^{1 –} Mann-Whitney U Test; 2 – Kruskal-Wallis Test; r_s – Spearman's rank correlation coefficient

employing people with epilepsy. Women, married persons, white-collar workers would more willingly employ a person with epilepsy. The position held and seniority did not statistically differentiate (p > 0.05) willingness to employ.

DISCUSSION

This research study which has been undertaken in adults living in the Greater Poland Voivodeship 10 years after an earlier study was undertaken has revealed that the level of knowledge among respondents has increased, but first aid education is still necessary (Talarska et al., 2014). The lack of knowledge with regard to the rules of conduct during a generalised epileptic seizure is often reported in the studies analysing attitudes or the level of knowledge about epilepsy (Elhassan et al., 2017; Abbasi et al., 2019; Assadeck et al., 2020). Therefore, respondents and researchers often request that education be provided on the specificity of the disease and the rules for providing help during a seizure (Santos et al., 1998; Njamnshi et al., 2009; Abbasi et al.,

2019; Assadeck et al., 2020). In our current research, the lowest score has been given to the part relating to the declared behaviour. Respondents would not marry a person suffering from epilepsy but would also object to such marriage to their closest family member. Furthermore, people with epilepsy themselves also emphasize the negative impact of the illness on finding a partner and starting a family (Mlinar et al., 2016). The positive attitude towards people with epilepsy usually refers to the functioning of the sick person in their further environment, however, it deteriorates when they refer directly to the subjects (Shehata, Mahran, 2011; Talarska et al., 2014; Kiwanuka, Olyet, 2018; Dargie et al., 2019; Akça, Kurt, 2020). The majority of positive answers were given to the question concerning friendship with a person suffering from epilepsy, a trend which can be observed also in other research studies.

Women, respondents who have completed higher education, are single, and those who work intellectually in our research would be more likely to employ people suffering from epilepsy and also have a more positive 32 Dorota Talarska et al.

perception of the affected individuals. Furthermore, the positive impact of education and female gender was also observed by other researchers (Santos et al., 1998; Karimi, Akbarian, 2016; Kiwanuka, Olyet, 2018; Dargie et al., 2019). In addition, the attitude is positively influenced if the respondents know a person suffering from epilepsy and if they have more knowledge about the disease (Talarska et al., 2014). In contrast, the low socio-economic status favours prejudice.

In comparison with the previous study, the perception of people with epilepsy as employees has improved. In the previous research 88% of the respondents believed that people with epilepsy should be employed, whereas now it amounts to 96%. Moreover, previously 80% of the respondents would be willing to work with a person suffering from epilepsy, now it has increased to 88%. In 2012 in Poland about half of people with epilepsy of working age were employed. What is more, they did both intellectual and technical work (Majkowska-Zwolińska et al., 2012).

In the UK, the 2018 report on the economic activity of the population indicated that more than half of people with epilepsy are not economically active. Despite anti-discrimination laws, individuals suffering from epilepsy are more than twice as likely to be unemployed compared to the rest of the population (Muller-Heyndyk, 2019). In addition, the study also revealed a lack of adequate knowledge among employers. The main cause of restricting the employment of people with epilepsy is the fear of having an epileptic seizure at work and the resulting risks (Jacoby et al., 2005; Murphy, 2017, Muller-Heyndyk, 2019). In fact, people suffering from epilepsy often conceal the disease from their friends and employers for fear of negative reactions (Jacoby et al., 2005; Mlinar et al., 2016). On the other hand, many employers stress the need to obtain information about the disease during job interviews (Talarska et al., 2014; Murphy, 2017). As a result, they could take measures to improve the safety and efficiency of work for employees with epilepsy, for example, by transferring part of their duties to other workers, giving extra breaks, offering flexible working hours or working from home (Jacoby et al., 2005). According to our study, as well as to other authors, employers of larger companies more often declare the possibility of employment (Jacoby et al., 2005).

The significance of work in the lives of people with epilepsy can be demonstrated in the study by Clarke et al. (2006), which compared employed and unemployed people with epilepsy. Individuals who were not profes-

sionally active stressed that work increased self-esteem and provided opportunities for independent living. However, they also emphasised that their families did not encourage them to take up employment; they did not have a proper education or feared that they would jeopardise their co-workers in the event of a seizure.

The authors concerned with attitudes towards people with disabilities point out that not only educational programmes and legislation are important in order to reduce discriminatory behaviour, but also well-thoughtout strategies based on the cooperation of all sources affecting society, such as school education, the media, associations working for the benefit of people with disabilities, lawyers or employers' associations (Mishra, 2018). The change of attitudes requires a longer period of time and requires the involvement of the majority of society (Mlinar et al., 2016).

Limitations

The obtained results require further research. Undoubtedly, an increase in the number and a greater diversity of the studied group would allow for a better understanding of attitudes in such groups as people with poorer education or among employees. In addition, a greater diversity of the group would constitute an opportunity to identify determinants of attitudes specific to a given level of employment.

CONCLUSION

Majority of people participating in the study showed a positive attitude. The study group had biggest difficulty answering questions about first aid and direct relations with the patients. Women, respondents with higher education, single and those who do intellectual work have a better perception of people with epilepsy. Most employers declared their willingness to employ a person with epilepsy. White-collar workers and women would employ more willingly and collaborate with a person with epilepsy.

CONFLICT OF INTEREST

The authors have no conflict of interest to declare.

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