

PSYCHOSOCIAL PROBLEMS AND PHYSICAL ACTIVITY AT DIFFERENT AGES IN PATIENTS WITH EPILEPSY

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ABSTRACT

Research background and hypothesis. Physical inactivity of patients with epilepsy is associated with the course of the disease, treatment, preconceived attitudes and myths that their physical activity might be dangerous and cause seizures (Steinhoff et al., 1996; Nakken, 2001).

The aim of our research was to examine the links between the psychosocial problems of patients' with epilepsy, their physical activity, self-reported quality of life as well as their connection with patients' age.

Research methods. The participants were 209 patients with epilepsy from three different regions (Šiauliai, Panevėžys and Pasvalys) of Lithuania. The subjects were selected with the help of quantitative closed-type survey – QOLIE-89 and IPAQ international questionnaire. The research findings were compared between two age groups: younger (20–39 years of age) and senior (40–59 years of age) subjects.

Research results. The main psychosocial problems for patients with epilepsy were concerns about possible injuries during the seizures, experience of shame and other social restraint, health problems that might occur as a result of taking antiepileptic drugs for a long period of time, negative effects of antiepileptic drugs and memory impairments. These problems were more common among younger respondents ($p < 0.05$). Physical activity levels in patients with epilepsy were inadequate and different. The main factor that contributed to these differences was patients' age. Younger respondents trained more in their leisure time, while seniors spent more time reading or sleeping ($p = 0.002$). Younger patients lacked knowledge about the most appropriate types of physical activities, senior respondents were inactive were to the disapproval of medical professionals and their health problems ($p = 0.006$). Younger respondents evaluated their lifestyle as good enough more often than seniors.

Discussion and conclusion. Psychosocial problems and physical inactivity of patients with epilepsy were connected with their age. Younger respondents more often than seniors were physically active and their self-reported quality of life was good.

Keywords: age of patients with epilepsy, social problems, physical activity, evaluation of lifestyle.

INTRODUCTION

Epilepsy is a common illness in the world (Bondstrata et al., 2008). Even 5.87 people out of 1000 are diagnosed with active epilepsy which requires medical treatment in Lithuania (SVEIDRA, 2008). Patients with epilepsy commonly experience behavioural, emotional and mood disorders due to psychological difficulties and epilepsy-related social restraints (Herman, Jacoby, 2009). In comparison with the total population, people with epilepsy have more psychological problems the number of which

grows proportionally to the frequency of seizures. O. Devinsky et al. (2005) claim that people with epilepsy have difficulties (experience discomfort), R. Mameniškienė et al. (2002) suggest that more than half of the patients are not inclined to control their disease consciously. Despite the modernisation of the society, there are still wrong concepts and ideas about patients with epilepsy resulting in difficult social environment for the patients (Laccheo et al., 2008). The specialists usually get only the information about treatment,

and psychosocial problems which are experienced by people with epilepsy are forgotten (Webe et al., 2001; Pennell, Thompson, 2009).

Physical inactivity of patients with epilepsy is associated with the course of the disease, treatment, preconceived attitudes and myths that physical activity might be dangerous and cause seizures (Steinhoff et al., 1996; Nakken, 2001). Many people with epilepsy reported general and epilepsy-specific barriers to leisure time physical activity (Kihye Han et al., 2011). Types and frequency of seizures, as well as medication may influence patients' ability to be physically active (Devinsky et al., 1995; Wong, Wirrell, 2006). The evidence shows that patients with good seizure control can participate in both contact and non-contact sports without harmfully affecting seizure frequency (Arida et al., 2008). According to K. O. Nakken (1999), regular and properly chosen physical exercises may reduce seizures for 36% of people with epilepsy. Physical activities may also help to avoid psychosocial problems as they improve health, mood, produce positive changes, relieve depression and anxiety, could be potential candidate for stress reduction in people with epilepsy (Arida et al., 2009). People with epilepsy are aware of the principles of treatment and appropriate patterns of life, however more than half of them are unwilling to accept adequate responsibility for their illness (Devinsky et al., 2007). We have not found reviews about the psychosocial problems of those ill with epilepsy and links between physical activity and lifestyle in connection with their age.

We hypothesize that younger patients with epilepsy demonstrate psychosocial problems associated with disease but sometimes they lack time for physical activity and they evaluate lifestyle as good or excellent. Senior patients with epilepsy have more psychosocial problems associated not only with disease but also with social difficulties, they are physically inactive and evaluate their lifestyle as bad.

The aim of our research was to examine the links between psychosocial problems, physical activity, self-reported quality of lifestyle of patients with epilepsy and their connection with age.

RESEARCH METHODS

Participants. Members from associations of people with epilepsy from three different regions of Lithuania (Šiauliai, Panevėžys and Pasvalys) participated in the research in 2008 and 2009. The

survey was conducted considering the respondents' agreement and permission given by the presidents of the associations. For the final analysis 209 respondents were selected out of the population of 220 participants because 11 respondents did not return their questionnaires.

All respondents aged between 20 and 59 years. The age at the onset of the respondents' epilepsy according to the median differed significantly in the two age groups: 107 persons, 20–39 years old (51 women and 56 men) and 102 persons, 40–59 years old (55 women and 47 men). The differences did not depend on gender of the respondents ($p = 0.25$). The majority of the respondents had university education (29%) or incomplete higher education (67%). The education of the respondents did not depend on gender ($\chi^2 = 2.229$; $df = 6$; $p = 0.897$).

Methods. The main research method employed was a questionnaire survey. Aiming to examine the psychosocial problems of the subjects we used a quantitative closed questionnaire survey QOLIE-89 (Quality of Life in Epilepsy) (Ware, Sherbourne, 1992; Hays et al., 1993). QOLIE-89 contained multi-item measures of emotional problems, social support and worry about seizures, medication effects, memory, pain, health perceptions and self - reported quality of life. The questions from International Physical Activity Questionnaire IPAQ (Ainsworth, Levy, 2004) were inserted to determine in what kind of physical activity the respondents were engaged and how much time they were physically active during the past seven days. Both questionnaires were translated into the Lithuanian language and adapted for the survey in Lithuania.

The patients' with epilepsy answers to certain QOLIE-89 questions were assessed on three-point, four-point and five-point scales: from 1 – extremely interfering, to 5 – not at all interfering.

The frequency of physical activity of patients with epilepsy was assessed using questionnaire answers to the following questions: in what kind of physical activity or sports respondents were engaged in everyday life (at work, at home or in the courtyard, moved from one place to another, lifted light objects, exercised, participated in sports and other physical activity), how often they were physically active (their breathing became intensified) for at least 10 minutes, how much time they devoted to physical activities during the past seven days. If persons had to make moderate effort during physical activity and his/her breathing became intensified, if he/she walked no more

than 10 minutes per day, their physical activity was considered to be of moderate intensity. The respondents were considered physically inactive if they failed to perform these physical activities.

The relation between psychosocial problems of patients' with epilepsy and their physical activity was presented by dividing respondents into two groups: group 1 – patients who self-reported their quality of life as excellent or fairly good, group 2 – patients who self-reported their quality of life as moderate, poor or extremely poor.

Data analysis was conducted using computer program for statistical analysis *SPSS 11.0* (originally, Statistical Package for the Social Sciences). Average assessment reliability was determined according to Student's t test. Aiming at analyzing the independence of two features χ^2 test was applied. The reliability of statistical differences was set at the significance level of $p < 0.05$.

RESEARCH RESULTS

Figure 1 demonstrates that the majority of younger respondents developed epilepsy in early childhood or adolescence, while many older patients were diagnosed with epilepsy at the mature age. The difference was statistically significant ($\chi^2 = 47.772$; $df = 5$; $p = 0.00$) and did not depend

on the gender of the respondents ($\chi^2 = 6.63$; $df = 5$; $p = 0.25$).

Table 1 indicates that illness-related feelings experienced by patients with epilepsy (assessed on a three-point scale) were not always related to their age. The point average shows that the majority of the respondents were extremely or slightly concerned about possible injuries during seizures, embarrassment and other social problems. Younger respondents were more concerned about these problems ($p < 0.05$). The survey also showed that more than half of the respondents of both age groups had concerns about sustained use of medications and their adverse effects ($p > 0.05$). Table 1 shows that anxiety about memory difficulties and social restraints was higher than the median (3.0), i. e. respondents were slightly anxious. Younger respondents were more concerned about these problems than the older ones ($p < 0.05$). The respondents of both age groups gave similar evaluations of the time spent with their family and close friends. Despite all psychosocial problems patients with epilepsy self-reported the quality of life as moderate. Significantly more respondents of the younger age self reported the quality of life worse than their older counterparts.

Table 2 demonstrates that the point average of strenuous exercise restrictions due to health

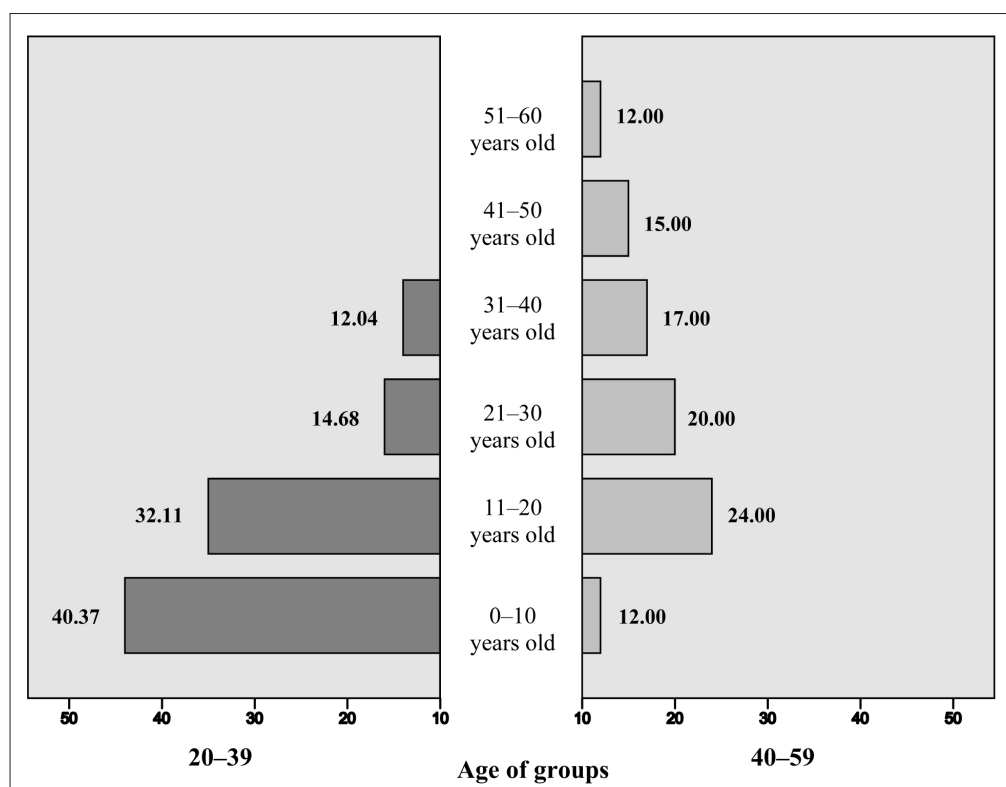


Figure 1. Patients with epilepsy grouped according to the onset of epilepsy (%)

was close to slightly limiting level of physical activity and did not depend on respondents' age. Lifting and carrying shopping bags were only slightly limiting or completely limiting factors among all respondents. During the past seven days respondents participated in physical activities only four times. Walking was also quite limited. The variety of responses revealed that some respondents went for a walk more than six times, others – rarely and for less than ten minutes per day.

Figure 2 shows that younger respondents were jogging, riding a bicycle or roller-skating during their leisure time, while senior patients most often were reading or sleeping ($\chi^2 = 40.27$; $df = 18$; $p = 0.002$).

The reasons for poor physical activity in younger patients with epilepsy (see Figure 3) were lack of information about appropriate physical activities and free time occupations. Senior

patients stated that they were physically inactive due to the lack of information, health problems and disapproval of medical professionals ($\chi^2 = 23.23$; $df = 9$; $p = 0.006$).

The self-reported quality of life in patients with epilepsy pertains to moderately intensive physical activity during the past seven days (Table 3). Among all the respondents who evaluated the quality of their lives as reasonably good, fewer patients were concerned about adverse effects of long term use of medication ($p = 0.038$), while all the rest were engaged in moderately intense physical activity during the past seven days ($p = 0.001$) and spent more quality time with their family and close friends ($p = 0.013$). Moreover, among the respondents who evaluated the quality of their lives as good and poor, the same numbers of patients were concerned about possible injuries during the seizures, embarrassment or social problems and went for

Table 1. Psychosocial problems of people with epilepsy (points)

Items	Values	Age groups		Significance of the difference	
		General	20–39	40–59	t
Worries about possible injuries during the seizure	1.83 ± 0.612	1.73 ± 0.60	1.93 ± 0.61	-2.363	0.019
Worries about embarrassment and other social problems due to seizures	2.04 ± 0.634	1.93 ± 0.61	2.15 ± 0.64	-2.486	0.014
Experienced difficulties performing the work or other activities during the past 4 weeks	3.05 ± 0.821	3.03 ± 0.81	3.07 ± 0.83	0.922	0.337
Worries about the adverse effect of long-term use of medications on health	1.64 ± 0.61	1.69 ± 0.56	1.60 ± 0.65	1.005	0.316
Anxiety about memory difficulties (forgetting names of people, places, other information, etc.)	2.93 ± 1.083	2.58 ± 0.99	3.29 ± 1.05	-4.917	0.000
Anxiety about social limitations	3.14 ± 1.01	3.22 ± 0.98	3.06 ± 1.03	1.133	0.258
Time spent with family and friends	2.71 ± 0.971	2.70 ± 1.05	2.73 ± 0.88	-0.239	0.811
Patients' self-reported quality of life	2.94 ± 0.773	2.67 ± 0.70	3.22 ± 0.75	-5.393	0.000

Table 2. Physical activity of people with epilepsy (points)

Items	Values	M ± SD	Age groups		Significance of the difference
			20–39 years	40–59 years	p
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	1.66 ± 0.59	1.66 ± 0.54	1.67 ± 0.65	0.874	
Lifting and carrying shopping bags	2.46 ± 0.60	2.39 ± 0.62	2.52 ± 0.58	0.125	
Intensive physical activities during the past seven days.	4.06 ± 1.68	3.85 ± 1.78	4.26 ± 1.56	0.092	
Walked for less than ten minutes per day during the past seven days.	5.22 ± 1.39	5.02 ± 1.47	5.41 ± 1.27	0.047	

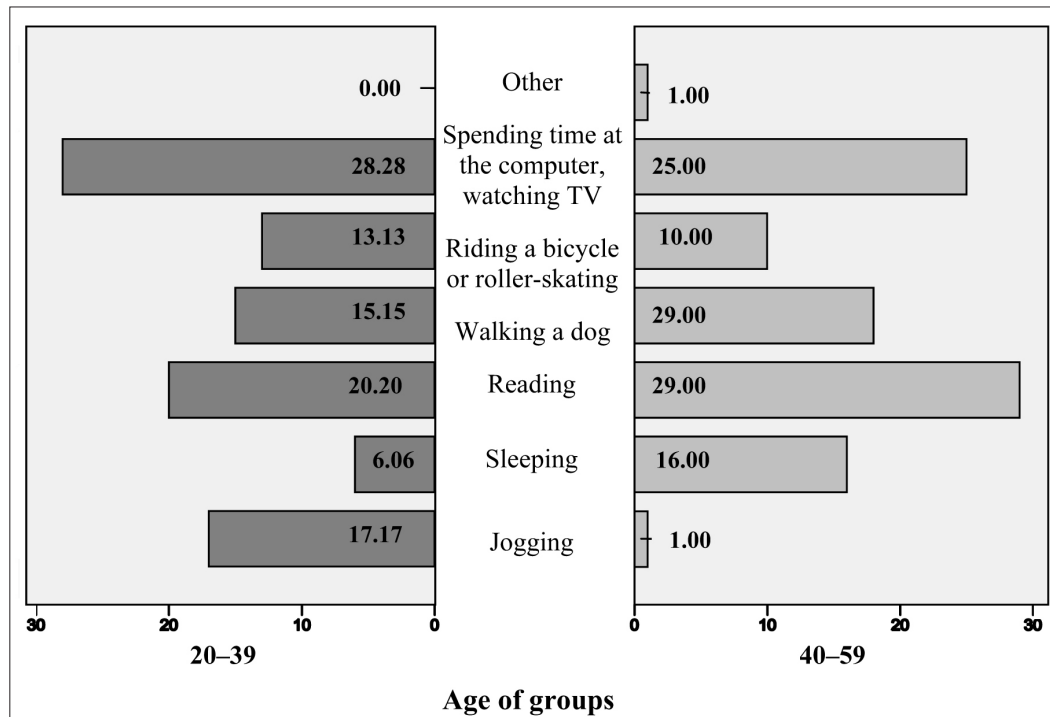


Figure 2. Leisure time physical activities of patients with epilepsy (%)

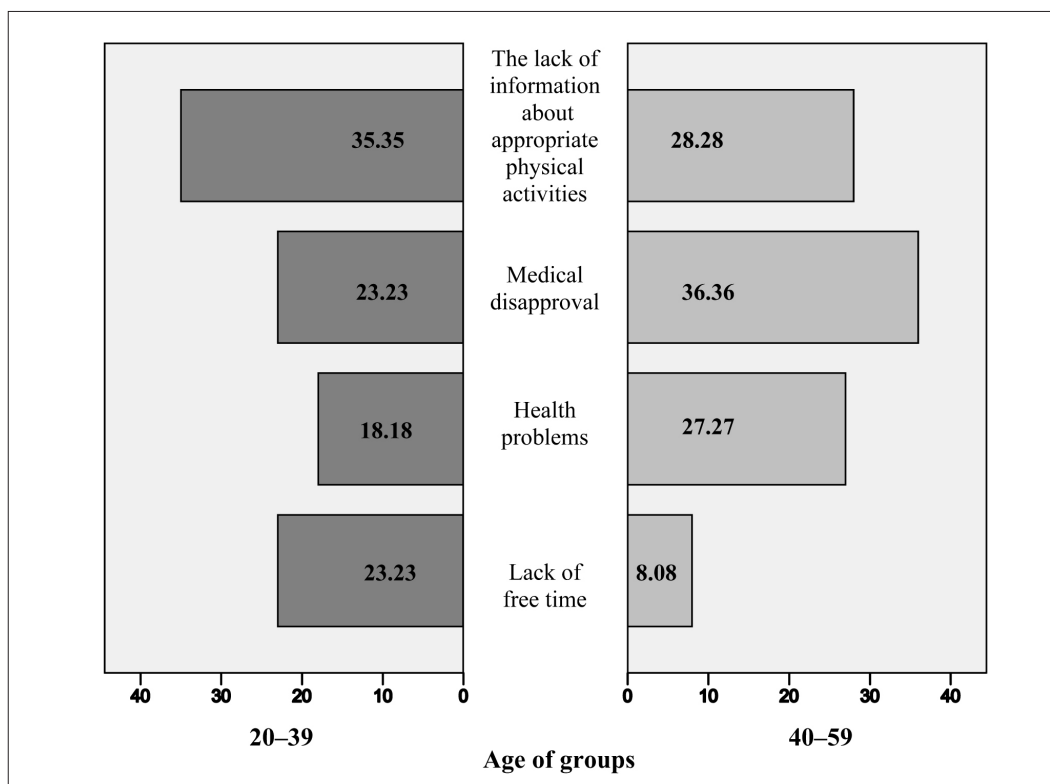


Figure 3. The reasons for physical inactivity in patients with epilepsy (%)

shorter than 10 minutes walks per day during the past seven days ($p > 0.05$). Spearman's correlation analysis revealed that there was a connection between the reasons discouraging physical activity

($r = -0.180$; $p = 0.011$), furthermore, the most common leisure activities were tangential to the evaluation of the quality of life during the past four weeks ($r = 0.153$; $p = 0.031$).

Table 3. Interrelations of self-reported quality of life, psychosocial problems and physical activity in patients with epilepsy (points)

Items	Values	Self-reported quality of life as excellent or fairly good		Self-reported quality of life as mediocre, poor or very bad		Significance of the difference
		N	M ± SD	N	M	p
Moderately intensive physical activities during the past seven days	60	4.63 ± 1.756	136	3.81 ± 1.594	0.092	
Walking not less than 10 minutes during the past seven days.	62	5.31 ± 1.455	137	5.18 ± 1.361	0.047	
Worries about possible injuries during the seizure	62	1.76 ± 0.534	137	1.86 ± 0.644	0.019	
Worries about embarrassment and other social problems due to seizures	62	1.95 ± 0.612	137	2.08 ± 0.642	0.014	
Worries about the adverse effect on health due to long-term use of medications.	62	1.77 ± 0.584	137	1.58 ± 0.614	0.316	
Time spent with family and friends	62	2.97 ± 1.101	137	2.60 ± 0.887	0.811	

DISCUSSION

According to S. Choi-Kwon et al. (2003) the quality of life among patients with epilepsy depends not only on the type and frequency of seizures, but also on the psychological and emotional state due to social stigmatization. Our research has demonstrated that 40% of younger respondents developed epilepsy during the first ten years of their lives (i. e. epilepsy was innate or childhood epilepsy), 32% of them developed epilepsy at the age of 11–20 (i. e. during adolescence). Hence the majority of 29–49 year-old respondents experienced the effects of epilepsy during their youth; the illness heavily affected not only them, but their families as well. In the senior age group a large number of patients had post-traumatic epilepsy. These respondents encountered the loss of employment, the necessity of retraining, financial difficulties.

Almost every person with epilepsy is concerned about possible injuries during the seizure. It was determined that younger respondents were worried about the injuries more often than the older ones because their social ties were wider, there was an increased probability that qualified medical aid might not be provided. Moreover, younger patients with epilepsy were more concerned about possible embarrassment and discrimination due to seizures, dependence on other people, behavioural changes and memory difficulties. C. Bagley (1972) indicates that just a while ago epilepsy was considered to

be a psychiatric disorder and people still follow myths when judging patients with epilepsy. Most often people who have developed epilepsy at an early age have an exaggerated perception about shame and discrimination, thus they might not be able to overcome more serious problems in the future (Devinsky et al., 2007). Older respondents were less worried about shame and other social problems.

According to the researchers (Kwan, Brodie, 2001; Lee, 2005) appropriate treatment can successfully control and even prevent seizures for most people with epilepsy, important predictors of good outcome are few side effects of therapy. Our research revealed that the majority of the respondents were taking antiepileptic drugs, and some of them experienced side effects. Due to the usage of antiepileptic drugs the respondents of the younger age group experienced difficulties and disturbance at work and were anxious about social limitations. A large number of senior respondents indicated that they were not greatly concerned about their illness and side effects of antiepileptic drugs, however with age their concerns increased. Many other authors agree with this opinion concerning the effects of antiepileptic drugs (Hesdorffer et al., 2011).

Patients with epilepsy very often tend to worry about memory difficulties; they suffer from a more severe cognitive function disorder. It has been scientifically proved that memory difficulties

frequently correlate with the severity of seizures, their frequency, medication used and other factors. Memory problems were also indicated by our respondents and they were related to the respondents' age. Younger respondents were not much concerned about memory difficulties. Increasingly, patients with epilepsy tended to worry about problems related to memory, which was particularly noticeable in the senior group (up to 75%).

A significant indicator, especially among younger respondents, was higher or incomplete higher education. Education received can help improve the quality of life for patients with epilepsy, make them aware of their health condition, ensure better activity and communication, their involvement in social life, opportunities to devote more time for family and relatives. The opinion of other researchers coincides with the fact that education has a great impact on the person's social possibilities (Daoud et al., 2007).

World Health Organization (WHO) recommends that every adult should get at least 30 minutes of physical activity per day. The recommended time should not be divided into shorter than 10-minute periods; however, it has been proved that even very short physical activities have a positive effect on health (Jankauskienė, 2008). Nowadays doctors try to encourage patients with epilepsy to be physically active; nevertheless, people are still physically inactive for fear of inducing seizures or increasing seizure frequency and due to the lack of information. Studies have revealed that physical activity can decrease seizure frequency as well as lead to improved cardiovascular and psychological health in people with epilepsy, especially with the help of physicians' encouragement and recommendations, accurate monitoring of medications, and preparation of family or trainers (Bjorholt, 1990; Howard et al., 2004; Pennell, Thompson, 2009).

The respondents who participated in our research were also quite intolerant to physical

activities. The majority of respondents were physically inactive as they feared to induce seizures, they lacked information about adequate types of physical activities. Despite all the positive effects of physical exercise, patients with epilepsy were still discouraged from participation in physical activities by physicians. On average, our respondents were physically active not daily, but only four times during the last seven days. Patients who were moderately physically active during the last seven days evaluated the quality of their life better than those who were physically inactive.

CONCLUSIONS AND PERSPECTIVES

1. Psychosocial problems and physical inactivity of patients with epilepsy were related to their age.

2. Younger respondents manifested the following psychosocial problems: antiepileptic medication interfering with their work; worries about social limitations; deterioration of memory, fear to experience shame due to seizures. The seniors demonstrated worries about the possibilities to lose their jobs, self-service limitations, social difficulties.

3. Patients with epilepsy were physically inactive. Younger respondents indicated that they lacked knowledge about forms of physical activity appropriate for them; sometimes they lacked time for physical activity. Seniors indicated that they were physically inactive due to health problems and discouragement from their doctors.

4. More physically active patients self-reported their quality of life as good, substantial or excellent. The younger respondents were more numerous among them as well as those patients who worried less about the harmful effect of medicine and spent more time with their friends and close people.

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EPILEPSIJA SERGANČIŪJŲ PSICHOSOCIALINĖS PROBLEMOS IR FIZINIS AKTYVUMAS

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SANTRAUKA

Tyrimo pagrindimas ir hipotezė. Sergančių epilepsija fizinis pasyvumas susijęs su ligos eiga, gydymu, ligonių požiūriu ir mitais, kad fizinis aktyvumas gali būti pavojingas ir išprovokuoti priepuolius (Steinhoff et al., 1996; Nakken, 2001).

Tikslas – išsiaiškinti sergančiųjų epilepsija psichosocialines problemas, fizinį aktyvumą, savos gyvenimos vertinimą ir pastarųjų sąsajas su ligonių amžiumi.

Metodai. Buvo tiriama 209 trijų Lietuvos rajonų (Šiaulių, Panevėžio ir Pasvalio), susibūrusių į epilepsija sergančiųjų draugijas, nariai. Naudojant kiekybinę QOLJE-89 anketą ir IPAQ tarptautinį klausimyną atlikta anketinė apklausa. Duomenys palyginti tarp jaunesniojo (20–39 metai) ir vyresniojo (40–59 metų) amžiaus apklaustųjų.

Rezultatai. Pagrindinės epilepsija sergančiųjų psichosocialinės problemos buvo nerimas, kad priepuolio metu gali susižaloti, patirti gėdą, rūpestis dėl socialinių apribojimų ar tai, kad ilgą laiką vartojami vaistai gali pakenkti sveikatai, pablogėti atmintis. Šias problemas nurodė daugiau jaunesnių nei vyresnių respondentų ($p < 0,05$). Epilepsija sergančiųjų fizinė veikla buvo menka. Didelis duomenų išsibarstymas rodė, kad epilepsija sergantieji fizinį aktyvumą vertina nevienodai. Dažniausia skirtumų priežastimi buvo sergančiųjų amžius. Jaunesni respondantai laisvalaikiu daugiau bėgioja, važinėja dviračiu ar riedučiais, vyresni – daugiau skaito ar miega ($p = 0,002$). Jaunesni respondantai nurodė, kad stokoja laisvo laiko ir žinių apie jiems tinkamiausią fizinės veiklos formą, vyresni – esą fiziškai neaktyvūs, nes tam nepritaria gydytojas ar to nedaro dėl sveikatos problemų ($p = 0,006$). Savą gyvenimą kaip pakankamai gerą įvertino daugiau jaunesnių apklaustųjų ir mažiau tų, kurie turėjo psichosocialinių problemų ar buvo fiziškai neaktyvūs.

Aptarimas ir išvados. Psichosocialinės problemos, menkas fizinis aktyvumas glaudžiai susijęs su apklaustųjų amžiumi. Fiziškai aktyvesnių ir nurodžiusių geresnę gyvenimo kokybę buvo daugiau jaunesnio nei vyresnio amžiaus respondentų.

Raktažodžiai: nerimas dėl ligos, socialinės problemos, fizinis aktyvumas, savos gyvenimos vertinimas.

Gauta 2013 m. kovo 7 d.
Received in March 7, 2013

Priimta 2013 m. birželio 7 d.
Accepted on June 7, 2013

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