How Much Stigma Can Influence the Development of Depression in Epilepsy?

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ORIGINAL PAPER
SUMMARY
Introduction: Epilepsy is the most common neurological disorder of the brain and also the least understood. Fear, misunderstanding and the resulting social stigma surrounding epilepsy can result in social, and sometimes even legal, discrimination against those living with this condition. Although attitudes toward people with epilepsy have improved over the years, for many people with epilepsy, stigma continues to adversely impact their psychological well-being and quality of life. Goal: To determine social and economic characteristics of the patients with epilepsy, presence of depression in comparison to duration of illness and stigmatizing circumstances. Material and methodology: Prospective study included 300 patients with epilepsy treated at the Ambulatory for epilepsies of the Clinical Center of Sarajevo University. Besides standardized questionnaire, all patients were tested using Beck Hamilton depression scales and GOLIE-31 questionnaire. Results: Our sample included 300 patients from both genders, where the male patients was slightly more dominant with the average age of 37.67 years +/- 12.86 compared to female patient which were significantly (p< 0.05) younger with mean age of 32.83 +/- 12.26. For the female patients average age of the first epileptic seizure was at 14.05 years +/- 8.55, and for males 19.53 years +/- 12.39. Significant difference is noted also regarding the marriage and work in favor of men’s, which is important stigmatizing factor for the women with epilepsy. Presence of depression was noticed among 34% of patients at the Beck Depression Scale, and 38.9% at the Hamilton scale with the significant difference in presence of severe depression among women. 14% of patients had suicidal ideas, which requires special attention during the treatment. Conclusion: Epilepsy stigma, recurrent epileptic seizures and early occurrence of epilepsy in life have significant influence on development of depression and quality of life, especially for women.

Keywords: epilepsy, stigma, depression, quality of life.

1. INTRODUCTION

Epilepsy takes an important role as a most frequent neurology illness, by respecting the fact that 1% of the general population suffers from this disease. Most common mental disorder that accompanies epilepsy is interictal depression, which lifetime prevalence varies from 40 up to 60% (1, 2).

Depressive symptoms are usually undetected, and because of that inadequately treated, which complicates and worsens the course and the outcome prognosis of the epilepsy. Attempts to measure the quality of life among epileptic patients are relatively new, and all in goal to have wider evaluation of the health care influence on this disease, more efficient treatment and resocialization of these patients.

We usually think of stigma as something that exists in the minds of other people, but many people with epilepsy internalize stigma, and can come to think of their condition as shameful and of themselves as undesirably different: less worthy, less capable, and more likely to encounter negative reactions from others. This in turn can lead to lower self-esteem, anxiety, depression, and quality of life (3).

The concept of stigma first gained popularity in social science research through the work of Erving Goffman. He defined stigma as an “attribute that is deeply discrediting and that reduces the bearer from a whole and unusual person to a tainted, discounted one.” In an effort to further Goffman’s definition of stigma, Link and Phelan propose that a stigma arises as a product of four social processes. First, people distinguish and label human differences. Secondly, dominant cultural beliefs link labeled persons to undesirable characteristics—to negative stereotypes. In the third social process, labeled persons are placed in distinct categories so as to accomplish some degree of separation of “us” from “them” (4).

Increased perceived stigma, amount of social support, poor vocational adjustment, external locus of control, increased stressful life events, poor adjustment to epilepsy, less adequate financial status, and female gender were all associated with interictal depression. The last four factors
remained statistically significant variables after multiple regression analysis (5)

In study conducted by J.K. Austin et al., the researchers surveyed the knowledge and attitudes of a large number of adolescents in the general population about epilepsy by administering a 37-item questionnaire. Specifically, they wanted to measure teens’ familiarity, knowledge and perceptions of epilepsy. Overall, few adolescents in the general population were familiar with epilepsy. Furthermore, respondents knew so little about epilepsy that most either did not know or were not sure about 7 of the 12 knowledge items in the questionnaire. Other findings showed that adolescents with epilepsy face an uncertain and possible hostile social environment. For example, because many respondents thought that epilepsy was contagious or a form of mental illness, adolescents with epilepsy might be socially isolated as a result of peer ignorance and confronted with coping with the emotional impact that social discrimination can create.(6)

Obtained results impose necessity for multidisciplinary approach in the treatment of epilepsies and to involve in a team besides neurologist and psychiatrist, also social


to duration of illness and stigmatizing circumstances.

2. GOAL
To determine social and economic characteristics of the patients with epilepsy, presence of depression in comparison to duration of illness and stigmatizing circumstances.

3. MATERIAL AND METHODOLOGY
Prospective study included 300 patients with epilepsy treated at the Ambulatory for epilepsies of the Clinical Center of Sarajevo University. Besides standardized questionnaire, all patients were tested using Beck Hamilton depression scales and QOLIE-31 questionnaire.

4. RESULTS
Sample included 300 patients from both genders, where

the male patients was slightly more dominant with the average age of 37.67 years +/- 12.86 compared to female

patient which were significantly (p< 0.05) younger with mean age of 32.83 +/- 12.26.

Difference in employment and marital status of patients according to gender was statistically significant.

According to Beck depression scale 34% of patients have depression, while according to Hamilton scale 38.9% have depressive change in the mood, and mild symptoms

for 23.6% of male and 24.3% female patients. Severely expressed depressive symptoms have double as much female

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Figure 1. Age distribution

Figure 2. Marital status

Figure 3. Employment

Figure 4. Beck depression scale

Figure 5. Hamilton depression scale
How worried you are due to embarrassment or other social problems as a result of depression which was much less concerned about possible injury. The difference among the genders is significant at the level p< 0.01.

Compared to baseline, we can notice that the presence of depression is in correlation with the duration of epilepsy at the significance level of p < 0.0001.

Women with epilepsy, who more often have depression as comorbid disorder, significantly more expressed concern that they will be embarrassed if they have the seizure during next month.

This concern also had the patients which did not fulfill the criteria for depressive disorder, opposite to men with epilepsy and without depression.

Regarding concern of possible injury during epileptic seizure in next month, more dominant were women, as with as well without depression, compared to men with depression which was much less concern about possible injury.

Fear from possible occurrence of seizure during next month was significantly present among women with epilepsy and comorbid depression, as well as women without depression. Men with epilepsy and depression were very concerned due to possible future epileptic manifestations.

On a question how in general they will evaluate their quality of life on a scale from worst (0) to the best possible (10), we received significantly different answers from depressed and not depressed patients. For the depressed patients mean evaluation of quality of life was around slightly worse life quality, and among not depressed around good life quality. In that manner male patients with depression have their peak value of slightly good and women neither good nor bad.

5. DISCUSSION

Statistically highly significant difference (p< 0.005) is noticed regarding employment, so that 40% of male patients is employed compared to one quarter of women, this speaks in favor of much more stigmatization and handicap among women compared to men, when speaking about advantage in employment. About 56% of our patients are unemployed, and 11% is retired, which is sign of poor economic status. This is important negative predictive factor for quality of life, especially is we have in mind the still present lack of anti epileptic medication of so called "new generation", and which are not on the list of drugs financed by the health insurance, and are necessary in treatment of epilepsies resistant to medication.

Regarding marriage, once again men are in advantage, we can notice that 40% is married, compared to 31.2% of women, which are more present in the group of divorced/widowed, with statistically significance of differences (p < 0.05).

If we observe the age when first epileptic seizure oc-
curred, we can notice that among women seizures significantly more often occurs during puberty (13-18 years) or in 413% of cases, compared to 18.5% of males at the same age group (p<0.0001).

Average age of the female patients was 14.05 years with SD +/- 8.55, and males on average had the first seizure with 19.53 years and SD +/- 12.39. Among middle age men significantly more was present first epileptic seizures compared to women, which is probably to great extent related to the occurrence of symptomatic epileptic seizures at this age.

In study done by Baker 2001, it is found that among men important predictor for development of depression is late onset of epileptic seizures (7).

Presence of depression was noticed among 34% of patients at the Beck Depression Scale, and 38.9% at the Hamilton scale with the significant difference in presence of severe depression among women.

This difference in presence of depressive symptoms in patients who suffer from epilepsy at the Beck’s and Hamilton scales is of special importance, considering that the patients who suffer from epilepsy are prone to negate and diminutive their problems, which may mislead doctors, so they overlook a serious depressive affective disorder and fail to recognize and treat depression on time. Importance of timely diagnosis of depression, earlier treatment is even more important because there is significantly higher percentage of suicide ideas in this group, and the literature has identified a large number of committed suicides among patients suffering from epilepsy.

Half of the patients are concerned a lot of time that they will have a seizure during the next month, primarily due to the possibility of injuries during the seizure.

In the study done by Cramer and associates 2003, there is significantly (p<0.0001) more depression among the patients with epilepsy who had frequent epileptic seizures, compared to patients who have established control of the seizures three months before testing. (8)

66% of respondents had a feeling of unease due to the fact that they will be embarrassed or to have other social problems, which may be the result of the seizure. Stigma is a significant parameter that affects the quality of life of people suffering from epilepsy, especially in younger age (9).

Over 60% of the patients are concerned about the negative impact of anti epileptic medication, which they are using for long time, especially women.

More than a third of patients stated that they are very disturbed by the seizures, with a leading role of men with epilepsy, significantly more due to working constraints, than the problems with memory and social restrictions.

Psychological effects of taking anti epileptic therapy were significantly greater problem that their physical effects.

On the question how their health status is good or bad (in the range 0-100), where 0 represents worst possible health and 100 best possible condition, two thirds of respondents had a response in the range of 50-90, which means that the total health conditions ranging from satisfactory to good. Numerous studies have shown the negative correlation between the frequency of epileptic seizures and the quality of life. Depression as a highly significant predictive factor for quality of life is also found Boylan 2004, in his research. (10)

6. CONCLUSION

Epilepsy stigma, recurrent epileptic seizures and early occurrence of epilepsy in life have significant influence on development of depression and quality of life, especially for women.

People with epilepsy often struggle to overcome low self-esteem and the stigma that is attached to having epilepsy. The stigma is due in part to a lack of understanding by people they see every day. Some people mistakenly believe that epilepsy is a form of mental illness or mental retardation, that seizures are something to fear, that drastic first aid measures must be taken to help someone having a seizure, or that people with epilepsy cannot be valuable and productive employees. Public education is needed to eliminate these misconceptions.

REFERENCES

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