

Received: 10.06.2010
Accepted: 20.10.2010

A – Study Design
B – Data Collection
C – Statistical Analysis
D – Data Interpretation
E – Manuscript Preparation
F – Literature Search
G – Funds Collection

PSYCHOSOCIAL ASPECTS OF EPILEPSY

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SUMMARY

Background

One of the factors which directly affects quality of life (QOL) in patients with epilepsy is society's attitude toward this disease. Despite considerable progress in the treatment of epilepsy, many patients continue to experience extremely prejudiced behavior from society, even in culturally and economically developed countries. The climate accompanying epilepsy is still replete with prejudice, magic and even contempt rooted in the superstitions and witchcraft which used to exist in mediaeval Europe. This article identifies the factors that mediate the emergence and consolidation of the false and negative image of patients with epilepsy.

Material/ Methods:

A clinical study was conducted at the Department of Neurology and Epileptology in Warsaw. We studied the determinants of changes in the emotional, cognitive and behavioural components of attitude.

Results:

Patients hospitalised for conditions other than epilepsy underwent a clear behavioural change and attitudinal re-evaluation with respect to patients with epilepsy. This leads to some tentative conclusions concerning the determinants and dynamics of change of attitude toward patients with epilepsy in the general population.

Conclusions:

Correct medical intervention in epilepsy involves not only accurate diagnosis of the type of epileptic syndrome and implementation of targeted pharmacotherapy, but also accurate diagnosis of all the elements contributing to QOL and level of satisfaction of the patients' medical, emotional and social needs.

Key words: social attitudes, quality of life, seizures

INTRODUCTION

Epilepsy is one of the most frequent disorders of the nervous system, and leads to many different diagnostic and therapeutic problems. It is caused by variously located unifocal or multifocal brain damage of various etiologies, and its onset may occur at any age. An estimated 50 million people all over the world have epilepsy (Majkowski 1985).

Two different concepts are used in epidemiology: incidence and prevalence. Incidence means the number of new cases of an illness per 100,000 population per year. Prevalence means the frequency of occurrence of an illness in a given population at a given time and is defined in terms of percentage of the population with the illness at a specified time. As far as epilepsy is concerned, the accepted incidence rate is 60/100,000 per year, and the accepted prevalence rate is 1,000/100,000. This means that at any given time, about 1% of the population has epilepsy. If we take into account the occurrence of at least one epileptic seizure, together with febrile convulsions, throughout the lifespan from birth to death, the risk of epilepsy is 8% for the general population of any society, of which only 10% will have recurrent seizures justifying a diagnosis of epilepsy. These figures clearly suggest that epilepsy is one of the most frequent neurological diseases, 10 times more frequent than multiple sclerosis and 100 times more frequent than motor neurone disease (Jędrzejczak & Owczarek 1995).

There are many types of epileptic seizures, and each type has different symptoms, such as brief seizures with loss of consciousness lasting several seconds or with no loss of consciousness. These relatively benign forms of epileptic seizure are called partial seizures. Benign seizures can also involve sensing strange smells, visual sensations or sounds. These seizure elements may be isolated or combined, in which case they may occur simultaneously or sequentially, one after the other. In the latter case we call them complex seizures. These incidents may occur with varying frequency, and their complexity and intensity may also vary. It is usually difficult to foresee where and when they will occur. There is still another type of seizures, usually accompanied by loss of consciousness and trembling of the whole body. Very often, during these convulsions, which usually affect the whole body, the person loses consciousness, and froth may ooze from the tightened mouth. This state lasts for about two to three minutes, then all the symptoms recede spontaneously. These seizures are called tonic-clonic seizures.

Epilepsy is a heterogeneous disease in terms of aetiology, course and health-related and social consequences. It cannot be defined, then, as a strictly medical, psychological or social problem. As we said before, as far as type and frequency of epileptic seizures is concerned, we can discern forms whose dynamics are sudden, with frequent seizures, loss of consciousness and generalized convulsions of the whole body, which are treatment resistant. Patients may also experience intellectual or motor disability and emotional

problems. It should be emphasised, however, that only about 20-25% of all patients with epilepsy have such problems (Majkowski 1985). For objective reasons, the level of social aspirations and life opportunities are often very restricted in patients with this type of epilepsy. However, in the vast majority of cases (75-80%), milder forms of epilepsy, with fewer seizures, tractable and completely controllable, are diagnosed. In this group of patients, intellect, memory and other cognitive functions do not differ from the population average, and developmental indices are also within the normal range. Some patients only have partial seizures, which cause minor and transient problems in sensory (auditory, visual) functioning or cognitive functioning (some mental operations may be affected or memory may be impaired by drugs). These limitations do not normally affect the day-to-day functioning of children and adults with epilepsy.

FREQUENCY OF EPILEPTIC SEIZURES AND QOL

When epilepsy is diagnosed, early optimal pharmacological treatment can be introduced together with appropriate psychological intervention. This way, many patients with epilepsy make major therapeutic progress and achieve considerable self-sufficiency, which has paramount importance for adequate social functioning and subjective improvement of QOL.

The effects of active epilepsy and epileptic seizures on psychosocial well-being are well documented (Betts 1981, Jacoby et al. 1998, Owczarek 2004). Baker and colleagues (1997) conducted a European-wide study of 5000 men and women with epilepsy. Respondents who had at least one epileptic seizure a month reported the most severe negative effects of illness and lowest QOL, whereas respondents who were free of seizures within the previous year rated the effects of epilepsy least negatively and had the highest QOL scores on the generic SF-36 scale.

US researchers have reported similar results. In a study by Leida et al. (1999), patients who had at least six seizures within the previous six months had lower QOL scores on the SF-36 than patients who had from 1 to 5 seizures, whose QOL was lower than the QOL of patients without seizures. These writers argue that the differences between the groups were very clear, suggesting that even a slight reduction in the number of seizures can improve QOL. In another American study of 40,000 Californians, the authors analysed the effect of seizure frequency on QOL during the period between the last seizure and the time of study, and found that adults who had a seizure recently rated their general health more negatively, reported more bad days (physical and psychological) and more days with limited activity than patients with active epilepsy who had not had a seizure recently. The latter, in turn, had poorer self-reported wellbeing than patients whose epilepsy was inactive or men and women who did not have epilepsy. It comes as no surprise that

patients noticed that active epilepsy and recent seizures affect their QOL. They also reported lack of physical activity and other co-occurring somatic conditions, and were less likely to be married or employed. The authors of a German study (May et al. 2001) distinguished six groups of seizure frequency within the previous six months. Group 1 had no seizures within the last six months, groups 2 and 3 had 1-2 seizures and 3-5 seizures respectively, group 4 had more than one seizure a month, group 5 had at least one seizure a week and group 6 had at least one seizure a day, the most of all. This study also found that QOL in epilepsy clearly depends on the number of seizures. Patients without seizures in the last six months had the highest scores on all questionnaire subscales, whereas patients with at least one seizure a week had the lowest QOL scores. The side effects of drugs and seizure severity also affect QOL, whereas QOL greatly improves in patients whose number of seizures drops to nil. Equally interesting is the attention which the German researchers (May et al. 2001) draw to an indicator which may help to assess seizure severity (acuteness), i.e. recovery time. According to the German researchers, recovery time is an important determinant of QOL in patients with frequent seizures.

In recent years there has been considerable progress in the pharmacological treatment of epilepsy, as attested by research reports on the safety and clinical effectiveness of new anti-epileptic drugs. The natural consequence of these new therapeutic advancements is an increasing number of patients with well-controlled seizures. Improved self-sufficiency and wellbeing naturally motivates patients to become involved in mainstream social life. However, patients meet many barriers on the road to normal and satisfying functioning. In their daily living, patients have to cope with many objective and subjective obstacles. Satisfaction with their QOL depends on how effectively they are able to overcome various deeply rooted social prejudices (Pačalska 2008). One of the reasons why patients with epilepsy are often stressed and depressed is that they feel stigmatised due to lack of acceptance or even intolerance of people like themselves.

THE SOCIAL PERCEPTION OF EPILEPSY

Thanks to the great progress which has been made in the diagnosis and treatment of epilepsy, it is now possible to greatly reduce the number of seizures and the associated discomfort in the vast majority of patients. Thanks to their improved subjective wellbeing and cognitive functioning, many patients do not experience the clinical consequences of their illness on a daily basis. Yet their social situation still fails to be normalised for reasons other than health. The reasons for the poor social functioning of patients with epilepsy are centuries-old prejudices, myths and superstitions, which sentence these people to a life in isolation (Owczarek 1998). Epilepsy continues to be viewed as a condition inseparably connected with aggression, mental retar-

dation and various psychiatric symptoms. Attitudes and behaviours rooted in gross generalizations lead to poor self-esteem, stigmatization and humiliation in patients with epilepsy. Trostle (1998) shifted the focus of interest of researchers of stigmatisation from the one who is stigmatised to the one who stigmatises when he said that "to have epilepsy is to open oneself to the full force of past and contemporary social prejudice and misunderstanding".

Surveys in affluent European countries have found that unequivocally negative character traits are attributed to persons with epilepsy. In the United Kingdom, patients with epilepsy are generally perceived by society to be hostile and aggressive, anxious and demanding or mentally retarded, asocial and physically repugnant (Jacoby et al. 1998). Studies of social attitudes toward persons with epilepsy in France have shown that the vast majority of the population do not want to work with persons with epilepsy, see no way of spending free time with them (sport, recreation) and do not want to live in the same neighbourhood with them (Dulac 1995).

Employers also have stereotyped views of epilepsy, have exaggerated fears and are reluctant to employ persons with epilepsy (Jacoby et al. 1998). However, the fewer seizures patients have, the greater their chances of employment (Jacoby 1995). Unemployment is certainly one of the main reasons for patients' sense of stigmatisation. Dutch researchers have found yet another sign of acutely unfair treatment of patients with epilepsy by employers. Patients with epilepsy are subject to various forms of intolerance as far as employment is concerned. Those patients who do manage to find a job and have the same qualifications as healthy persons are paid much less for the same work. Researchers have also drawn attention to the higher rate of suicide attempts in patients with epilepsy who are having difficulty finding a job (Lassouw et al. 1997).

Patients vary in their ability to cope with social stigma and the ensuing limitations. Studies of subjective sense of stigmatisation have found that it correlates positively with low self-esteem, low self-confidence, low sense of control, helplessness, high anxiety, depression and higher frequency of subjective somatic complaints, and lack of satisfaction with life (Collins 1990, Jacoby 1994, Baker et al. 1999). Overall QOL seems to be particularly deficient in patients with epilepsy who feel stigmatised. A Dutch study (Suurmeijer et al. 2001) found that a sense of stigmatisation is the fourth most important determinant of low QOL, after psychological stress, loneliness, and level of adjustment. This study also found that stigmatisation is twice as powerful a predictor of QOL variance as such clinical factors as seizure frequency or the adverse effects of anti-epileptic drugs.

Diagnosis of epilepsy has far-reaching consequences for QOL throughout the lifespan and is becoming a much more serious therapeutic challenge than strictly medical issues. Recent studies of the reasons for social discrimination of persons with epilepsy suggest that 50% of persons with epilepsy experience humiliating signs of discrimination because of their illness on a daily

basis (Baker et al. 1999). It is very important to remember that the sense of stigmatisation does not depend on frequency and type of seizures. Simply being labelled "epileptic" is enough to attract stigmatising behaviour. According to some researchers, tolerance toward persons with epilepsy is greater in more economically developed and affluent countries. Chung et al. (1995) conducted a comparative study of economically underdeveloped China and economically affluent Taiwan and found beyond doubt that tolerance of persons with epilepsy was greater in Taiwan. The positive correlation between affluence and tolerance in the United States of America confirms this pattern. However, the findings of a European study (Baker et al. 1999) suggest that the reasons for greater tolerance in various societies are not as simple as that. Generally speaking, the authors' conclusions seem to corroborate earlier findings (Jacoby 1994, Betts 1981, Jacoby et al. 1998, Collings 1990) that the feeling of patients with epilepsy that they are being discriminated against because of their illness is accompanied by depression, anxiety and low self-esteem. Significant differences in intensity of negative attitudes toward epilepsy were found in the European countries studied. The highest percentages of discriminating attitudes were found in France, Greece, and Germany, whereas persons with epilepsy felt least discriminated against in Poland, Spain, and Denmark (Baker et al. 1999). This means that the level of experienced discrimination depends on place of residence, and that normative systems (customs, traditions, law etc.), rather than personal traits, are the factors which determine attitude patterns toward epilepsy. In other words, we must look for the reasons for social prejudice and prejudiced behaviour in factors which are present or absent in social mores.

In many countries, prejudice seems to be the outgrowth of years-long failure to cultivate tolerant social attitude patterns and to popularize information about epilepsy (Owczarek 1999). One way to overcome these false stereotypes is to modify the inaccurate image of persons with epilepsy in social perception. There are still many myths and stereotypes concerning both the causes of epilepsy and the day-to-day functioning of persons with epilepsy.

One major misunderstanding which has negative social consequences is the oversimplified, consistently negative image of persons with epilepsy. Dramatic seizures with loss of consciousness and convulsions have shaped the social image of all patients with epilepsy. Research conducted by social psychologists (Aronson et al. 1997) has shown that people base their opinions on frequently inadequate schemas and theories which simplify reality. Images and ideas become more realistic and accurate mainly through direct contact with the object of judgement, in which case one's knowledge about the object of judgement becomes more objective, complete and factual. This postulate also applies to attitudes toward persons with epilepsy. A study conducted at the Department of Neurology and Epileptology in Warsaw (Owczarek 1999) looked at attitudes toward persons with epilepsy in patients admitted to hospital for reasons other than epilepsy. In order to assess change in attitude

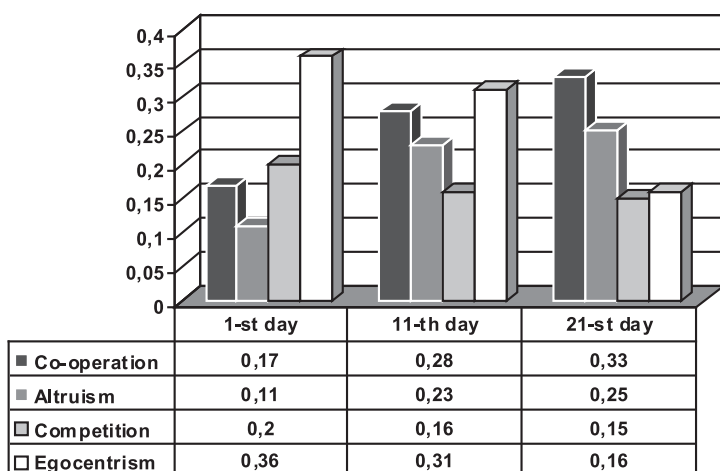


Fig. 1. Non-epileptic patients' attitudes toward epileptic patients (Owczarek, 1999)

during hospitalization, participants were examined three times in succession. The analyses showed that attitudes towards persons with epilepsy evolved in a directed and systematic way.

On day one, individualistic and competitive or even hostile attitudes were prominent. Within the first 10 days, attitudes towards patients with epilepsy became increasingly compassionate, positive and accepting. After three weeks of sharing quarters at hospital, attitudes were even more positive. Cooperation and altruism had increased, whereas egocentrism, hostility and competition had decreased markedly. Hence, within just three weeks, the initial negative image of persons with epilepsy had changed dramatically. This change was brought about by personal contact with patients with epilepsy. It is important to point out that initial negative attitudes sprang from lack of information or even erroneous conceptions of epilepsy. Change of attitude evolved gradually as participants developed a realistic image of patients with epilepsy, and this personal experience helped them to overcome their initial negativity and stereotypical prejudice. Our results suggest that, under certain circumstances, it is possible to modify deep-set social attitudes within a very short time. Better knowledge of the object seems to be the key factor in such attitude modification. If so, then it may be possible to eliminate false conceptions and prejudices from human consciousness by providing information accessibly and convincingly. We must remember, however, that at the social level such attitude modification is a long process, requiring consistent and prolonged educational intervention.

SOCIAL ATTITUDE MODIFICATION AND QOL

The findings of research on attitudes towards persons with epilepsy suggest that it is possible to change these attitudes rather quickly. The factors

which seem to play the greatest role in such positive re-evaluation are direct experience and contact with persons with epilepsy. In natural settings this process may last much longer due to lack of sufficient information (or even erroneous ideas concerning epilepsy) and lack of personal experience. In hospital settings, social mechanisms operate rather differently and specifically. On the one hand, when people are staying together in the same place while experiencing a problem situation, their “communality of experience” may facilitate the development of cooperative attitudes. But on the other hand, dependence on medical staff, especially physicians, may facilitate the development of competence-related attitudes in the hospital setting. Also, illness and distress are not very conducive to altruism. Yet our respondents, who were hospitalised for reasons other than epilepsy, clearly experienced a positive re-evaluation of attitudes towards patients with epilepsy in the general population. It is noteworthy that no psychotherapy in any form was conducted during the study, and so we can conjecture that our participants’ emotional re-evaluation was triggered by enriched personal experience and increased self-knowledge. By informing about epilepsy adequately, convincingly and accessibly, we may be able to eliminate myths and popular prejudices from social consciousness.

We must bear in mind, however, that this process is not so simple and obstacle-free in macro-social conditions. Here, intervention must be long-term and come from sources which the target trusts. When moulding and changing attitudes we use three pathways:

- the cognitive pathway, where the main method of intervention is providing information about the attitude object (here: epilepsy);
- the emotional pathway, where the main method of intervention is evoking emotions and feelings toward the attitude object;
- the behavioural pathway, where the main method of intervention is evoking specific behaviour relating to the attitude object.

Change of attitude is usually brought about by intervening along more than one pathway, because messages do not normally contain only emotional arguments or only rational arguments.

Due to the considerable advantage of negative associations resulting from deficits in the cognitive pathway, argumentation should mainly contain information concerning the disease (at the same time we can expect the emotional climate to change).

As far as important social issues are concerned, attitude change usually comes about in response to modification of normative systems, i.e., mores and customs, the dominant religion, tradition and legislation. Nowadays, mass media have the most ubiquitous effect on social norms. It is increasingly obvious that attitudes change in response to many different external social factors, and that only to a very slight extent do they change in response to internal processes. Hence the educational perspective on epilepsy should be viewed in terms of large-scale social campaigns involving the media and sci-

entific authorities.

The better we understand the social mechanisms of attitude formation, the more successful we will be in our efforts to encourage positive re-evaluation of persons with epilepsy. One positive example is the outcome of a comparative study conducted in the USA (Jacoby 1995). In 1949 only 45% of adult Americans thought that persons with epilepsy should be employed, but by 1979, 79% of adult Americans endorsed this opinion. Commentators of this positive change in attitude argue that the dissemination of accurate information about the disease has greatly contributed to this change of attitude. The aforementioned comparative African (Jilek-Aall et al. 1997) and Asian (Chung et al. 1995) research on regions differing greatly in level of education and knowledge of epilepsy sheds some interesting light on this problem. This research demonstrated that in those regions where there is no tradition of rational treatment of epilepsy and superstition substitutes for sound knowledge about this disease, prejudice and stigmatisation are very widespread.

The psychosocial issues discussed in this article are very important for patients' subjective QOL. It is these aspects of patient functioning which are now becoming a standard element of the complete clinical assessment of patients with chronic diseases, because they often have a negative effect on every aspect of life: physical, psychological, social, emotional, family and occupational. Epilepsy is one of these diseases which have a heterogeneous aetiology (CNS damage) and a specific course: it lasts many years, while the onset of epileptic seizures is sudden and unexpected. Correct medical intervention in epilepsy means not only correct diagnosis of the type of epileptic syndrome and choice and implementation of the correct pharmacotherapy. It also means correct assessment of all the elements of QOL and degree of satisfaction or lack of satisfaction of the patient's various medical, emotional and social needs. Only when epilepsy is diagnosed in this complex way will it be possible to implement comprehensive treatment – not only pharmacological treatment, but also various forms of psychological, psychiatric, social and occupational interventions, according to the patient's needs and potential. Assessment of QOL in patients with epilepsy will not only lead to genuine improvement of treatment outcomes, it will also help to reduce the global, social costs of treatment of epilepsy.

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