

SAMOPOMOČ NA PODLAGI LASTNIH IZKUŠENJ V POVEZAVI Z EPILEPTIČNIMI NAPADI

SELF-HELP BASED ON SUBJECTIVE EXPERIENCES IN CONNECTION WITH EPILEPTIC SEIZURES

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Izvleček

Lastne izkušnje o epileptičnih napadih so osnovna informacija o tem, kako je imeti epileptični napad. To znanje je pomembno za izobraževanje bolnika, samonadzor epileptičnih napadov in nujno za razvoj ustreznih terapevtskih ukrepov, ki temeljijo na bolnikovi perspektivi. Z raziskovanjem izkušenj bolnikov pospešujemo nadaljnje raziskave o povezavah med lastnimi izkušnjami bolnikov in »objektivnimi« meritvami, ki bodo pripomogle k boljšemu razumevanju epilepsije.

Ključne besede:

rehabilitacija, epileptični napadi, samonadzor, subjektivne izkušnje, spoprijemanje

Abstract

Subjective experiences in connection with epileptic seizures are the core information about how it is to have a seizure. Such knowledge is important in patient education, self-control of seizures and necessary for developing adequate therapeutic interventions that are based on patient perspective. Also, by studying subjective experiences, we can promote further research on the relationships between subjective experiences and "objective" measurements in order to gain a deeper understanding of the phenomenon of epilepsy.

Keywords:

rehabilitation, epileptic seizures, self-control, subjective experience, coping

SELF-HELP BASED ON SUBJECTIVE EXPERIENCES IN CONNECTION WITH EPILEPTIC SEIZURES

Subjective experiences related to a certain condition are the keys for understanding how it is like to have that condition. This knowledge is also necessary for developing adequate therapeutic interventions that are based on the patient perspective. Although the quality of subjective experiences has long been used for localization and lateralization of epileptiform activity for example in epilepsy surgery (1, 2) and they have frequently been described in clinical contexts, there has been a lack of systematic descriptions from patient perspective.

The fact that concepts and methods have been developed that enable categorizing of subjective experiences related to partial epileptic seizures in a reliable fashion opens the possibility for studying e.g. the neural underpinnings of disordered consciousness in more detail (3-6). But also

making sense of the strange and often unpleasant subjective experiences is an important way to help the patient living with this condition which is the most important message of this paper.

SUBJECTIVE EXPERIENCES IN CONNECTION WITH SEIZURES AS SELF- HELP

Specific to epilepsy is the dramatic experience of undergoing a seizure and the losing control of one's behavior. Some of our patients have described experiences during partial seizures "as to die" or "crossing the border and then coming back". Such experiences can be unpleasant and frightening. They can lead to feelings of alienation and loneliness. But by sharing these experiences with other patients with epilepsy for example in therapy groups or self-help groups and thus putting them into a perspective, feelings of alienation and loneliness may decrease, which in turn increase the psy-

chological well-being (7). This is very important because failure to express and deal with negative feelings has been suggested to be an important factor in the development of depression (8).

Further, what it is like to have an epileptic seizure may be difficult to express in words. A great deal of seizure-related subjective experiences are distorted and bizarre compared to normal waking experiences. Consequently many of them are described by metaphors and some appear not to be possible to verbalize at all (4). Health care staff needs to be aware of this difficulty and of the fact that the ability to describe these experiences is a process which may take time. Further, there are some methods available (9-11) and hopefully more are to come.

This difficulty to verbalize experiences may also be a problem in communication between the patient and the examiner. It has actually been proposed that although subjective experiences characterize most complex partial seizures of temporal lobe origin, they are often neglected in clinical practice (12).

COPING STRATEGIES AS SELF-HELP

It has been reported that patients with epilepsy have less active coping strategies than the general population (13). The attitude that powerful other people, such as doctors, nurses, family, and friends, have control over their health status is strong among patients with epilepsy (14). The tendency of having less active coping strategies may at least partly be explained by fact that patients hope for remission. To wait is actually an adequate coping strategy until some time after having got the diagnosis, because most patients become seizure-free with the first or second AED. However, if the seizures continue, it is important that the health care staff help the patient to realize the benefits of active problem-solving strategies (10).

One of these strategies is the early recognition of certain subjective experiences as a sign of a coming seizure. Active problem-solving techniques have been observed to be positively associated with better mental health (15, 16) as are also an internal sense of personal control which has been found to be related in positive ways to psychological and physical well-being (13, 14).

PATIENT EDUCATION

When asked what people with epilepsy want from hospital clinics most of them express the need of more information about epilepsy and a possibility to talk to someone other than a consultant about epilepsy (17). This is interesting, because on the other hand, self-esteem of people with epilepsy has been seen to increase with increased knowledge

of epilepsy. Furthermore, the attitude a person has towards her/his epilepsy has been seen to influence the quality of life more than how difficult seizures are (18).

In clinical work, we have frequently observed that even after having had epilepsy for decades, surprisingly many patients have very little knowledge about their own epilepsy or about epilepsy in general. This includes often also a difficulty in describing their own seizure process. Consequently, helping patients to describe their seizure related experiences, describe their seizure related behaviour, and helping them to describe the seizures according to their temporal progression, is a valuable knowledge (3). Patients can use this knowledge when reflecting over their seizure in order to find ways for countermeasures to stop seizures, and when communicating with professionals about their epilepsy.

SELF-HELP GROUPS

For many people with epilepsy self-help groups give great support. Together with the local Epilepsy Association we have developed a model for self-help groups. They consisted of 8 group meetings during 3 hours each and one follow-up meeting, 7-9 participants in each group. The leader was educated and supervised by a neuropsychologist through all the 10 years these groups were running. She was the organizer of all the meetings and the leader of the discussions. Furthermore, a neurologist and a neuropsychologist were invited once each for every group.

HOLISTIC NEUROREHABILITATION FOR PEOPLE WITH EPILEPSY LEADS TO SELF-HELP

Brain damage may be a reason for or a consequence of epilepsy and therefore neurorehabilitation should be included in comprehensive epilepsy rehabilitation. Epilepsy (and brain dysfunction) may also lead to a deep-rooted negative effect on self-image. In order for treatment to be successful and to have positive effects on patients' lives and their ability to cope with epilepsy in the long run, a rehabilitation programme has to foster positive changes through integration of knowledge and insight into the self (7). Through learning to treat epilepsy as an issue to be managed, patients can reduce their fears and became more able to deal with problems.

Whatever the context leading to self-help – the WHAT – we should never forget the importance of HOW it is done. The basic therapeutic approach should include an emphasis on developing a client-centred approach. A major aspect of this is active listening and developing empathy for the patients or as some of our patients put it, “it was very important to be believed”.

To summarize, subjective experiences in connection with epileptic seizures are a valuable source of information in patient education, self-control of seizures and other kind of treatment approaches. Whenever it is possible the aspect of self-help should be included even if the rehabilitation needs of people with epilepsy differ greatly. Further, health care staff should help people who have epilepsy to become more active in their own treatment.

SUPPORT FROM THE LEGAL SYSTEM

It is well known that employed people have better psychological well-being with less negative feelings, such as depression and anxiety, than unemployed. At the same time, there are several studies which show that people with epilepsy have been found to experience difficulties in finding and maintaining employment (19), and there is also evidence of higher rates of unemployment and underemployment than in the general population (20).

The legal system gives people with illnesses and disabilities some support. These people when employed cannot be given notice of dismissal without strong reasons. They are also protected against discrimination on grounds of their disabilities. Furthermore, the employee has to have competence in how a certain job can be adapted or modified to a particular employee. Special considerations should be given those employees with disabilities.

As an example, Sweden has an ordinance called Job Modification and Rehabilitation (21) that states: "Particular reference should be considered if the individual employee has any disability or other limitation of working capacity". Further, according to the Work Environment Act "This Act is applicable to any business in which an employee performs work on behalf of the employer. The employer shall make allowance for the employee's special aptitudes for the work by modifying working conditions or taking other appropriate measures. In the planning and arrangement of work, due regard shall be paid to the fact that individual persons have differing aptitudes for the tasks involved" (21).

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