

## PSYCHOLOGICAL INTERVENTIONS IN THE CARE OF PEOPLE DIAGNOSED WITH EPILEPSY

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This article explores psychological interventions in the care of people diagnosed with epilepsy. The paper includes a literature review of the types of psychological interventions and the most effective psychotherapeutic interventions used in epilepsy centres. The focus is on identifying the most effective current methods, techniques, and psychological interventions for improving cognitive, affective, and behavioural processes in subjects with epilepsy. The article reveals the complexity of psychological interventions at the cognitive level which include compensatory strategies in cognitive rehabilitation (memory, attention, and language), psychological strategies at the affective level and psychological techniques at the behavioural level. Thus, we believe that psychological interventions can contribute to increased emotional stability, increased self-confidence, increased compliance with medication, increased trust in medical professionals, openness to society - all of which contribute to increased quality of life for people with epilepsy.

**Keywords:** *psychological interventions, psychological strategies, psychotherapy, epilepsy.*

### INTERVENȚII PSIHOLOGICE ÎN ASISTENȚA PERSOANELOR DIAGNOSTICATE CU EPILEPSIE

În acest articol sunt abordate intervențiile psihologice în asistența persoanelor diagnosticate cu epilepsie. Lucrarea cuprinde o analiză a literaturii de specialitate privind tipurile de intervenții psihologice, cât și cele mai eficiente intervenții psihoterapeutice utilizate în centrele specializate în epilepsie. Accentul este pus pe identificarea celor mai actuale metode, tehnici și intervenții psihologice pentru îmbunătățirea proceselor cognitive, afective și comportamentale în cazul persoanelor cu epilepsie. Articolul dat relevă complexitatea intervențiilor psihologice la nivel cognitiv care includ strategii compensatorii în reabilitarea cognitivă (memoria, atenția și limbajul), strategii psihologice la nivel afectiv și tehnici psihologice la nivel comportamental. Astfel, considerăm că intervențiile psihologice pot contribui la sporirea stabilității emoționale, sporirea încrederii în sine, creșterea nivelului de complianță la tratamentul medicamentos, creșterea încrederii în specialiștii medicali, deschiderea către societate – toate acestea contribuind la creșterea calității vieții persoanelor cu epilepsie.

**Cuvinte-cheie:** *intervenții psihologice, strategii psihologice, psihoterapie, epilepsie.*

### Introduction

The impact of epilepsy extends far beyond the direct effects of epileptic seizures and includes a series of medical, psychological, social, educational, personal, and economic challenges that can lead to disability and a significantly reduced quality of life. Psychological therapies have been developed to approach epileptic seizures and the psychological problems associated with epilepsy. Cognitive, affective, and behavioural changes in epilepsy determine specific methods of psychological intervention. Right from the onset of the disease, the diagnosis of epilepsy causes distress, anxiety, depression, social isolation, fear of stigma, low self-esteem, and a sense of loss of control over one's own life due to loss of independence, job, and financial income. This new reality initially generates shock, anger, stress, and denial associated with guilt and self-blame.

It is well known that a chronic illness causes a lot of suffering, and people with epilepsy are no exception. In this sense, a particularity of epilepsy lies in the dramatic experience of the epileptic seizure - an event that introduces a fracture in the person's relationship with reality and an ambivalent reaction in relation to the environment, which simultaneously becomes on the one hand hyperprotective and on the other fright-

ening and repulsive. The personality of the person with epilepsy is organised around this unpredictable repetition of seizures and secondary rearrangements staged by the subject and/or his entourage. Thus, H. Beauchesne (1976) considered that the way in which the entourage gives a meaning to the seizure is crucial in the organization of the subject. He also argues that it is always necessary to place the illness in a story that considers the personality at the time, the occurrence of epileptic seizures and the personality rearrangement introduced by these seizures [3].

Despite the progress of drug treatments in epilepsy, about 30% of people with epilepsy suffer from drug-resistant epileptic seizures [14]. In this context, psychological support is very important for these people, because the high frequency of epileptic seizures and the long duration of the disease cause progressive cognitive decline, accentuate affective states, and cause specific behavioural changes.

Despite awareness of the effectiveness of psychotherapeutic interventions for depression and anxiety, they have been insufficiently researched in epilepsy. A study reviewing the effectiveness of psychological treatments in epilepsy (Ramaratnam *et al.*, 2008) concluded that due to the limited number of studies and methodological concerns, there is insufficient evidence to support the positive effect of psychological treatment in epilepsy. The authors reviewed randomised trials of psychological treatments in epilepsy and identified anxiety in three studies (Sultana, 1987; Helgeson *et al.*, 1990; Olley *et al.*, 2001). The interventions used involved psychoeducation programmes, relaxation techniques and behavioural therapy. The results of the studies have been mixed – some studies found no change following psychotherapeutic treatment (Helgeson *et al.*, 1990), while other studies found significant reductions in anxiety symptoms (Sultana, 1987; Olley *et al.*, 2001). Depression was identified in six studies, in three studies psychoeducation was used (Helgeson *et al.*, 1990; Olley *et al.*, 2001; May and Pfaffl, 2002), the other two studies used cognitive-behavioural therapy (Davis, 1984; Tan and Bruni, 1986), and the third study used relaxation techniques combined with behavioural therapy (Sultana, 1987). In conclusion, half of the intervention outcomes reported no change following psychotherapeutic intervention (Tan and Bruni, 1986; Sultana, 1987; May and Pfaffl, 2002), and the other half reported improvement in depressive symptoms (Davis, 1984; Helgeson *et al.* 1990; Olley *et al.* 2001) [18].

Another study (Fisher *et al.*, 2000) found that 17% of 1,023 subjects in the United States showed interest in alternative therapies, although psychological therapies were used less frequently (biofeedback therapy – 2%, breathing/relaxation techniques – 0.4% and mind control – 0.1%) [10]. Other researchers (Haut *et al.*, 2003) found that just over half of the subjects surveyed were willing to engage in stress reduction therapies [12]. This illustrates that there is a demand for alternative treatment and people do not rely exclusively on taking antiepileptic drugs. However, just as one drug cannot be used for all people with epilepsy, so too individual psychological counselling depends on several factors, including lifestyle, individual intellectual abilities, and the person's motivation to change.

According to the psychological practices of European clinics specializing in epilepsy and the recommendations of the ILAE Neuropsychology Task Force, the following psychological interventions have been identified [6, 16, 22].

### **Cognitive psychological interventions**

In epilepsy, compensatory strategies within cognitive rehabilitation are used to minimise the impact of these impairments on daily life and to maximise functioning and improve the quality of life of people living with epilepsy. It is important to consider multiple factors that affect cognitive processes, such as age and onset of illness, seizure type and severity, controlled versus drug-resistant epileptic seizures, comorbid psychiatric diagnoses, and development of coping skills. Despite awareness of the impact that these cognitive impairments have on people with epilepsy, cognitive rehabilitation and psychological interventions are not applied as frequently as they could and should be in people with epilepsy. Considering the multiple cognitive domains that can be affected by epilepsy, the adverse effects of antiepileptic drugs, and psychological comorbidities, rehabilitation planning must necessarily be personalised to the needs of the individual. This makes interventions implemented in cognitive rehabilitation a challenging task.

The ILAE Neuropsychology Task Force Commission recommends compensatory strategies for people with epilepsy both to prevent cognitive decline and to train cognitive processes to cope with difficulties in everyday life [22]. These are associated with educational, vocational and community support in the psychosocial functioning of people with epilepsy [8, 22].

In the early 20th century, cognitive rehabilitation was focused exclusively on the remediation of brain dysfunction (i.e. the recovery of cognitive processes). More recently, cognitive rehabilitation is focused on behavioural compensation to reduce daily difficulties experienced because of brain dysfunction [21]. Cognitive rehabilitation is always preceded by a psychological assessment that focuses on assessing the needs of the person with epilepsy, identifying cognitive deficits, examining emotional and behavioural issues and other medical conditions that affect daily functioning [ibid 21]. It is essential to note that for successful cognitive rehabilitation, individuals must be aware of, recognize their own deficits, and accept the rehabilitation program as helpful. On the one hand, it is necessary to explain to them how these deficits can affect their lives and how they can develop coping and adaptive skills to their individual challenges, and on the other hand, professionals need to help them improve their weaknesses in cognitive domains and maximize their strengths [8].

*Strategies for memory.* Memory deficits can impact on social activities, as forming and maintaining relationships depends in part on the ability to do and hold social activities, retain information about others, and previous conversations. Thus, effective interventions to improve memory are crucial to improving quality of life and community participation. One of the oldest and most common ways to improve memory is practice. Studies show that compensatory trainings and strategies are effective in memory improvement and cognitive rehabilitation in people with epilepsy [17, 21]. Rehabilitation approaches to memory impairment usually focus on two techniques: restorative and compensatory. The goal of the restorative technique involves practice exercises and repetition, while the compensatory technique is based on the premise that memory does not need to be restored, the focus is on performance of daily memory tasks, which can be improved if the person learns effective strategies to service lost memory skills. Compensatory strategies used include the use of visual imagery techniques - practice, rehearsal, fragmentation, organisational and self-teaching strategies, as well as external help - reminders to perform the task, written interventions on paper and the use of technical devices. Other examples of compensatory strategies involve a notepad with calendar (things to do, addresses and phone numbers), smart phone (with alarms for reminders of appointments and activities, speech recording), lists, medication box etc. [8].

*Strategies for attention.* Interventions for attention deficits involve training activities that include repetitive target detection exercises in the presence of distractions and sorting words into alphabetical order (underlining the letters M and F in a newspaper, sorting numbers in ascending order, sudoku, puzzles, card games, „find the differences”). For people with high levels of motivation and compliance, cognitive exercises are recommended for one hour a day, 5 days a week.

*Strategies for language.* Recommendations for improving language include allowing time to respond, use of indirect language (talking around the word), visualization, gestures, written format, cues/signs from others, reading aloud, asking questions, and use of synonyms and antonyms [17].

Thus, cognitive, and emotional process training leads to increases in people's self-efficacy beliefs, particularly in their confidence in cognitive and emotional management, which improve both people's subjective well-being and quality of life.

### **Affective psychological interventions**

Psychotherapy is an integral component of the psychological rehabilitation programme in epilepsy, the aim of which is to develop self-awareness, explore feelings of loss and anger and restore the meaning of life. Psychotherapy, together with other counselling methods, helps to adapt and accept illness and disability by strengthening the therapeutic alliance. Establishing trust and providing a safe environment of acceptance underpins any successful psychological interventions that increase engagement in the rehabilitation process. Therefore, in the following we will describe the types of psychotherapies used in epilepsy:

*Psychoanalytic psychotherapy* is a form of psychotherapy, a method of research and a theory of the functioning of the psychic apparatus. Psychodynamic psychotherapy shares the aim of cultivating the ability to recognise what is not conscious – i.e. precisely what is difficult or painful to see in ourselves [4]. Psychoanalysts recommend a psychotherapeutic approach to the person with epilepsy and family counselling in which the fears and anxieties raised by seizures of people with epilepsy and their family members are listened to [3]. Clarification of disease onset, causes, prognoses, interventions, and treatment management reduces family anxiety. At the same time, extreme attitudes of both overprotection and unjustified rejection by relatives should be avoided. Psychoanalytic psychotherapy allows the crisis to be reintroduced into the person's history and provides a sense of crisis that can be psychologised and integrated.

*Cognitive Behavioural Therapy (CBT)*. A definition of CBT includes investigating how an individual interacts with their environment, developing and reinforcing positive behaviours, analysing the 'core' of the problem from which the behaviours (symptoms) arise, identifying maladaptive thoughts and behaviours and subsequently replacing them with more helpful behaviours and coping strategies [5]. In epilepsy this type of therapy requires modifications in technique – the hyperventilation method being contraindicated – as this can cause an epileptic seizure. The application of CBT in seizure reduction involves both addressing the negative thought processes associated with epileptic seizures and attempting to equip individuals with more control over their seizures [20]. Psychotherapy is usually individual, but can also be in groups, has clearly defined goals, is time-limited, and is focused on current problems.

*Family therapy* is characterised by the fact that the whole family is seen together, psychologists have concluded that in many cases the origin of a person's problems lies in the existence of family problems. Thus, the therapist's attention is not focused on an individual person, but on interactions within the family. In these sessions, special attention is paid to unconscious processes and past events that have current effects. Family therapy is an essential component in the management of epilepsy especially for the person with drug-resistant epilepsy, as the person with uncontrolled medication seizures rarely lives alone, in many cases remains single and lives with parents. Psychological consultations usually take place with family members, who are also in a constant state of tension and fear, ready to intervene with first aid in the event of a seizure. In this sense, family counselling helps the family to avoid blaming the person for his or her illness and helps the family to achieve a new family homeostasis. At the same time, it is important to listen to the anxieties caused by epileptic seizures of people with epilepsy and their family members during the sessions. Clarification about epilepsy, its causes, prognoses, interventions, advice on first aid in the event of a seizure and treatment management reduces anxiety in the family and helps to integrate the disease psychologically [2, 3, 21].

*Art therapy* allows people to explore their emotions and feelings through the process of creating, painting, and drawing. Art therapy offers alternative means of coping for people living with a chronic illness. S. K. Langer, an American art philosopher, has defined art as the „objectification of feelings”, noting that through art a person can express difficult feelings and experiences and learn to live with these painful experiences. The goal of art therapy is to process emotions, reduce stress and anxiety, increase self-confidence, and manage behaviour. In this regard, the American social psychologist S. Schachter in his book „Visions: Artists Living with Epilepsy” included a unique collection of artworks by people with epilepsy, reflecting the feelings and emotions of these people, highlighting abilities rather than disabilities [19].

*Music therapy* involves using the sounds of music to maintain and improve mental and physical health. It has been found that music can release inner tension and facilitate the expression of emotions that could not be expressed verbally, as well as having beneficial effects in reducing anxiety, depression, insomnia, stress, chronic pain, hypertension, learning difficulties. Classical music has been shown to influence cognitive centres, stimulating memory, logical thinking, spatial orientation, and attention [7]. Despite numerous studies demonstrating the positive effect of music on epileptic seizures, M. J. Maguire argues that the effect of music is complex and poorly understood, the author refers to musicogenic epilepsy which implies that, in extremely rare cases, particular sounds or music can trigger an epileptic seizure [15].

*Group psychotherapy* involves discussing a common problem with people who have similar problems. In the group, negative emotions of anger, frustration, anxiety, guilt, hopelessness, helplessness can be externalised and processed thanks to the support provided by the group. During group therapy, people are encouraged and helped by the therapist and other group members to find the most effective solutions to their problems. It is beneficial for them that other people with similar problems feel the same way, and the discussions can help them understand how they appear and how they can cope with them [7].

*Supportive counselling* is an essential element in every psychotherapy. Key components include conversational style, therapeutic relationship building, self-esteem improvement through praise and reassurance, anticipatory guidance, and advice on increasing adaptive skills through clarification and gentle confrontation [1]. In epilepsy, the psychologist focuses supportively on a reality of epileptic seizure behaviour, helping the person overcome denial, accept the illness, understand its manifestations, and facilitate cooperation with antiepileptic treatment.

*Psychoeducation* is a fundamental component in the rehabilitation programme, the aim of which is self-awareness for effective disease management. This therapeutic intervention is designed to engage, educate, and support the subject with epilepsy and their family members. Educational approaches include written materials containing information on brain function and the causes of cognitive impairment, individual sessions, and group sessions. Quite frequently family members are included in psychoeducational sessions. In group sessions for educational information purposes, people with epilepsy discuss the typical problems they face in a less threatening way. Through this approach, listening to the problems of others, their experience, and the difficulties they face, self-acceptance is promoted. These group activities provide an opportunity for individuals to learn about the cognitive, affective, and behavioural sequelae of epilepsy in a non-threatening way, helping to improve general knowledge, self-acceptance, correct false beliefs about epilepsy and psychosocial functioning in general [13, 16]. In this regard, Gilham (1990) demonstrated the effectiveness of psychoeducation in drug-resistant epilepsy [11].

Other successful psychological therapies in epilepsy include relaxation therapy or autogenic training, biofeedback therapy (neurotherapy), eye movement desensitization and processing (EMDR), clinical hypnosis, integrative psychotherapy, animal-assisted therapy, and mindfulness-based cognitive therapy (MBCT) [6, 7, 12]. Also, in working with people with epilepsy we consider important the professional consultative approach that encourages active listening allowing subjects the opportunity to discuss their problems. At the same time, we highlight the importance of the central role of coping and emotional well-being, as well as the importance of family factors in adaptation and acceptance of the disease.

### **Behavioural psychological interventions**

While the medication approach searches for the effective dose of antiepileptic treatment and investigates adherence to medication, a behavioural approach involves inserting seizures into an agenda, describing the situations in which they occur and preictal and postictal emotions, representations, and premonitory signs. In this regard, Fenwick (1995) used the ABC (antecedent, behaviour, consequences) technique to propose individually specific behavioural interventions for each subject [9]. The Andrews/Reiter programme (Reiter. et al.,1987) also examined the individual paternity of behaviour, emotions and external factors that could precipitate seizures with the aim of developing positive behaviours and stopping seizures. Compared to drug treatment that is gradually increased to achieve a therapeutic level in seizure control, positive behaviour adjustments may take longer to achieve a desired score.

Thus, an individualised approach to behaviour management includes a functional analysis of identifying the source of the behaviour, antecedents, and consequences. Functional analysis is extracted directly from observing and interviewing the person, the family, and the treating physician. Thus, by generating hypotheses from the collected data we can predict the triggers for the occurrence of the behaviour. Once triggers are identified - we understand when and why, we can prevent and change behavioural consequences. The behaviour optimisation programme also includes the development of self-confidence and self-esteem, ver-

bal and non-verbal communication, assertiveness, cooperation, initiative, creativity, spontaneity, as well as improving interpersonal and social integration skills [6, 20].

In conclusion, we can mention that psychological treatment is necessary because there are many people who do not achieve seizure control with antiepileptic drugs alone or do not want to take them. At the same time, it has been shown that psychological treatment helps people to take control of their seizures to a certain limit, therefore psychological therapy remains rather as an adjunct to pharmacotherapy and not a substitute.

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