

A psychosocial view of anxiety and depression in epilepsy

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Abstract

The aim of this study was to study anxiety and depression in patients with epilepsy and evaluate their relationships with neuroepilepsy and psychological variables. neuroepilepsy and psychological variables. Sixty patients and 60 healthy subjects were interviewed at the outpatient clinic for epilepsy, using the Beck Depression Inventory and State–Trait–Anxiety Inventory. The objective of the semistructured interview was to identify the patients' perception of the disease, self-concept, personal strategies, and perception of seizure control. There was a significant difference in anxiety and depression between the groups, as well as a strong relationship between perception of seizure control and depression and anxiety, independently assessed. Epilepsy was associated with disease (63.4%), mental problems (11.6%), feelings of shame, fear, worry, and low self-esteem (56.6%), and perception of stigma (26.6%). The strategies were: looking for social support, seeking medical treatment, withdrawal, denial, and spiritual support. There was a significant association between psychological symptoms and perception of seizure control, which reinforces the importance of subjective aspects involved in epilepsy.

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1. Introduction

Many are the exigencies or internal/external demands that are appraised as overburdening an individual's personal resources. Dealing with these stressful situations demands cognitive and behavioral efforts that may or may not be efficient. A chronic disease such as epilepsy can be an important stress factor, and inability to deal with the condition can bring psychological difficulties and emotional discomfort.

The cognitive model proposes that psychological disorders come from a misconceived or dysfunctional way of perceiving events, influencing affection and behavior [1,2]. The affective and behavioral symptoms of depression are influenced by the negativistic cognitive patterns that generate a tendency to react negatively in the face of difficulties and losses. In anxiety, the thought flow is more related to the danger and personal inability to deal with situations

that are appraised as threatening or without control, causing sensations of personal vulnerability [3]. In epilepsy, Hermann et al. [4] demonstrated that an attributional style was significantly associated with increased self-reported depression, even when such variables as age at onset, laterality of temporal lobe epilepsy (TLE), and gender were controlled. Attributional style is a component of the genesis of depression in epilepsy, as it is in the general population [4].

Because the impact of biological variables is less clear, authors like Robertson et al. [5] and Hermann et al. [6] suggest that psychosocial factors are better predictors of depression than biological variables. In anxiety, symptoms may result or be exacerbated by psychological reactions, including responses to the unpredictability of seizures and restrictions on normal activities, resulting in low self-esteem, stigmatization, and social rejection [7]. Efforts to control and adapt to stressful situations, as in a chronic disease, are developed through experience by each individual.

The responses to the stressor, cognitive or behavioral, have the objective of maintaining the perception of person-

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al control, although when insufficient, they can cause psychological disorders. Representation of the disease, self-concept, personal strategies, perception of social support, and perception of seizure control are important contingencies in adaptive reactions and mood control.

Our objective in this study was to identify anxiety and depression in individuals with epilepsy and to compare them with healthy individuals. We searched for a relationship among anxiety, depression, and clinical variables, as well as with the perception of seizure control.

2. Methods

2.1. Subjects

The subjects were 28 men and 32 women selected from patients who had epilepsy for more than 2 years and who were attending the Epilepsy Outpatient Department of the University Hospital (UNICAMP, Campinas, Brazil). The control group was made up of 20 men and 40 women selected from individuals who used to accompany the patients to the same hospital. Both patients and controls were between 20 and 45 years old and did not have any evident psychiatric disease or mental retardation.

From each pair of eligible patients, one was selected to participate in this study. Written informed consent was obtained from both patients and healthy individuals. The Committee of Ethics in Medicine of the University Hospital, UNICAMP, approved this study.

2.2. Instrument

All of the subjects completed an identification card on which they provided demographic data (age, educational level, socioeconomic level, profession) and epilepsy data (age at onset and duration, seizure frequency, type of seizures, and medication(s) used). Seizure frequency is expressed in days, months, or years. The frequency of seizures is classified as follows: very frequent, seizures occurring several times a day or at intervals shorter than 7 days; frequent, seizures at intervals longer than 8 days but shorter than 30 days; occasional, seizures at intervals longer than 31 days but shorter than 1 year; rare, seizures at intervals longer than 1 year.

A semistructured interview containing 10 questions on subjective aspects of the disease was used. Seven open-ended questions were aimed at identifying the meaning given to the disease, self-concept, feelings associated with having seizures, as well as difficulties faced in their lifetime, personal strategies, perception of support, and other problems not related to epilepsy. Three closed questions were aimed at identifying epilepsy as a stressor, perception of stigma, and perception of seizure control.

The data on perceived control of seizures was obtained through patient reports, in which they evaluated whether

their seizures were controlled or not. These data were subjective and may reflect alterations in the intensity and/or frequency of the seizures.

Depression and anxiety measurements were based on psychological protocols. The Beck Depression Inventory (BDI) [8], a 21-item self-report, was used to measure depression. The items are scaled from 0 to 4, according to depression intensity. It has good psychometric properties [9]. The Brazilian adaptation was made by Ferreira [10].

To measure anxiety, we used the State–Trait–Anxiety Inventory (STAI) [11]. The Trait scale refers to the stable predisposition of individuals to developing the anxiety state. Many researchers worldwide are interested in this test, and it has been translated into more than 20 languages. A Portuguese version of the STAI was validated for use in Brazil by Biaggio et al. [12]. This inventory was used in this study, after semantic validation, in such a way that it was easily comprehensible to the patients of the outpatient clinic for epilepsy at this hospital.

2.3. Procedure

Following selection and neurological evaluation, all subjects were individually interviewed at the Outpatient Clinic of Psychology applied to Neurology at the University Hospital of UNICAMP, Campinas, Brazil. The conditions of evaluation were the same for all subjects.

2.4. Statistical analysis

Statistical analysis was carried out to compare the groups. The CATMOD procedure, from the SAS Statistical System, was used with the log-linear model for categorical variables. Fisher's exact test and the Mann–Whitney test were also used. For categorization of continuous variables, descriptive statistics were used (mean, SD, maximum and minimum value per groups).

2.5. Demographic and clinical characteristics of the study sample

Table 1 lists these characteristics. The average age of the subjects (patients) was 32.43, and that of the controls, 34.13. In general, controls had received a better education, although in both groups, most individuals had not completed elementary school. Most of the patients did not have professions outside the home, unless one considers the great number of women who dedicated their time to unpaid domestic duties (Table 1).

The age at seizure onset varied from 1 to 37 (mean = 17.32), and duration of epilepsy ranged from 2 to 36 years (mean = 15.18).

Type of epilepsy and epileptic seizures were classified according to the International League Against Epilepsy classification of epilepsies and epileptic syndromes [13]. Fif-

Table 1
Demographic and clinical characteristics of subjects and controls

	Subjects	Controls
<i>n</i>	60	60
Female/male	32/28	40/20
Age (mean ± SD)	32.43 ± 6.61	34.13 ± 8.26
Age at onset of seizures (mean ± SD)	17.25 ± 9.5	
Disease duration (mean ± SD)	15.18 ± 9.2	
Focal seizures	17 (28.3%)	
Focal + generalized seizures	34 (56.7%)	
Generalized seizures	9 (15%)	
Temporal lobe epilepsy	35 (58.3%)	
Extratemporal epilepsy	16 (26.6%)	
Very frequent (1–7)	19 (31.7%)	
Frequent (8–30)	16 (26.6%)	
Occasional (31–180)	2 (3.3%)	
Rare (>180)	23 (38.3%)	
Illiterate	4 (6.7%)	3 (6.25%)
Elementary school	52 (86.35%)	43 (68.7%)
High school	4 (6.7%)	12 (21.25%)
Start college		2 (3.75%)
Employed	35 (58.3%)	45 (75%)
Unemployed	1 (0.01%)	
Housewife	19 (31.6%)	15 (25%)
Retired	5 (8.34%)	

ty-one subjects (84.6%) had partial seizures, which in 34 of these subjects were accompanied by secondary generalization. Nine (15.4%) had primarily generalized seizures. Among the 51 patients with partial seizures, 35 (67.4%) had temporal lobe epilepsy (TLE).

With respect to statistical analysis of seizure frequency, both occasional and rare groups were considered as one group ($n = 25$, 41.6%). There were 19 patients (31.7%) in the very frequent group and 16 (26.6%) in the frequent group.

Fifty-eight patients were under monotherapy and two were using two drugs. The most frequently used drugs were carbamazepine, phenytoin, sodium valproate, and phenobarbital.

3. Results

The meaning of epilepsy and other subjective aspects could be identified at the semistructured interview (Table 2).

The tests showed anxiety (33.3%) and depression (31.6%). Depression and anxiety trait were significantly associated ($P = 0.02$), as were anxiety state and anxiety trait ($P = 0.06$).

In Fig. 1, it is possible to see that in the subject group, 40.63% of women and 21.43% of men had depression. In the control group, 7.5% of women and 20% of men manifested this symptom. Fisher's exact test indicated there was no significant difference with respect to depression between women and men (subject group: $P = 0.165$; control group: $P = 0.208$). In the subject group, 43.75% of women and 28.57% of men had anxiety. In the control group, 12.5% of women and 10% of men had this symptom. Fisher's

Table 2
Representation of disease, self-concept, adaptive strategies, and perception of seizure control

	<i>N</i>	%
Epilepsy as		
Disease	38	63.4
Mental problem	7	11.6
Family burden	28	46.6
Losses and disvalue	25	41.6
Self-concept and feelings		
Abnormality	17	28.3
Being different	19	31.6
Being sick	16	26.6
Shame, worry, insecurity, and low self-esteem	34	56.6
Epilepsy as stressor	28	46.6
Difficulties		
Work	32	53.4
School	27	45
Relationship	16	26.6
Leisure	11	18.3
Sexual	30	50
Marriage	22	36.6
Perception of stigma	16	26.6
Adaptive strategies		
Looking for social support	24	40.1
Withdrawal	29	48.3
Looking for medical treatment	60	100
Nonacceptance, not talking about disease	35	58.3
Praying or looking for spiritual support	10	16.6
Looking for physical support (in the occurring seizure)	19	31.6
Others problems not related to epilepsy	7	11.6
Financial	5	8.4
Alcoholic in the family	1	1.7
Prostitution		
Perception of seizure control		
Controlled	40	66.6
Not controlled	20	33.3

exact test indicated that there was no significant difference in anxiety between women and men ($P = 0.1$).

Fisher's exact test revealed a significant difference in anxiety and depression between the subject group and the control group ($P = 0.014$ and 0.002 , respectively). Statistical analysis demonstrated no significant difference in depression and anxiety trait or anxiety state among the disease variables (age at onset of seizures, disease duration, type of seizures, or antiepileptic drugs).

Anxiety was observed in 11 patients who had very frequent seizures, in 5 patients with frequent seizures, and in 6 with occasional/rare seizures. It was possible to see a tendency in the association between frequency of seizures and anxiety trait ($P = 0.06$). The association between frequency of seizures and depression was not significant ($P = 8$).

TLE was not related to anxiety ($P = 0.108$) or depression ($P = 0.159$). In contrast, perceived seizure control was highly related to depression ($P = 0.009$) and anxiety ($P = 0$).

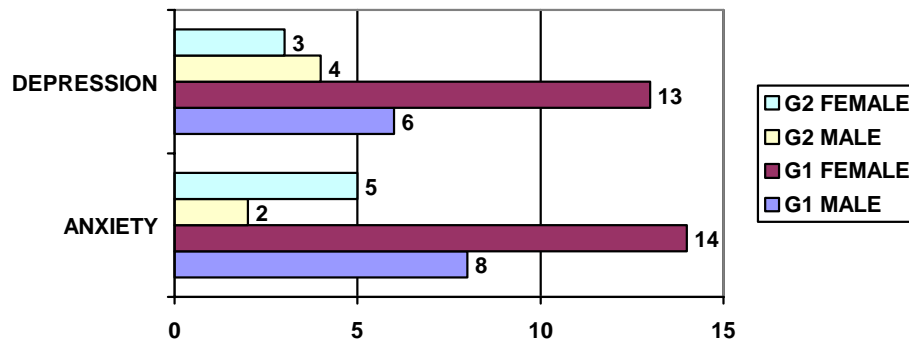


Fig. 1. Relationship between depression and anxiety and gender.

4. Discussion

Although several studies are in agreement that anxiety and depression are more frequent in people with epilepsy than in the general population, there is wide divergence with respect to the determining factors [14–18]. It is possible that some of the controversy in the literature is due to selection bias and insufficient consideration of both biological and psychosocial risk factors. Hermann et al. [18], in a literature review related to psychological disorders in epilepsy, classified the potential risk factors into four categories: (1) neuroepilepsy (age at onset, laterality and disease duration, etiology, and seizure type); (2) psychosocial (adjustment to epilepsy, perceived stigma and discrimination, and stressful events); (3) medication (monotherapy vs polytherapy, blood levels); (4) sociodemographic (age, gender and education).

Most of the articles have focused on the biomedical variables [19,20], but these have been shown to have modest predictive power [18,21]. Medication [22,23] and psychosocial variables [24–30] were less frequently appraised; however, they have been more significantly associated, mainly with depression [18,21]. Smith et al. [24] and Baker et al. [31] reinforce the role of subjective conditions and disagree with authors who tend to focus on illness variables.

In this study, 33.3% of the subjects with epilepsy had anxiety and 31.6% had depression, more frequent than in the control group. These symptoms were not associated with TLE and other disease variables (onset, duration, medication), strengthening interest in analysis of psychological conditions besides disease variables.

Although researchers have attempted to find a direct relationship, Quiske et al. [32] have shown that TLE can be one factor of vulnerability to the development of mood disorders in focal epilepsy. However, it has already been reported that depression in patients with focal epilepsy can also be determined by external and reactive factors [4,33,34]. In the current article, we have tried to deepen the psychological considerations of the relationship between depression and anxiety in epilepsy.

Workers in this field have made progress in the research on psychological health in epilepsy by examining the role of cognition and coping style [21,35]. Leventhal and Ner-

enz [36] affirm that patients with chronic illness build a cognitive representation of the disease and use strategies accordingly. A person's beliefs in symptoms, diagnosis, label, causality, perception of duration, consequences of the disease, and perception of control [37] integrate into his or her concept of "self" with implications for feelings, behavior, and adjustment. The psychological interview allowed qualitative analysis of the subjective variables.

This study covered dysfunctional beliefs related to the meaning of the disease. Epilepsy was associated with mental problems, losses, difficulties, and feelings of personal devaluation. It was also associated with feelings of shame, fear, concern, low self-esteem, and insecurity, which reinforce the self-concept of abnormality, of being different, and of being sick, as observed in the self-reports.

Dealing with the disease is a continuous process of evaluation of the signs of disease with cognitive structures to modify or to reinforce the representation of the disease as a factor under control or not and, consequently, stressful or not. These interpretations are extremely individualized. Irrational beliefs and feelings of insecurity and abnormality can many times derive from the interpretation of their living situations as stressful, because of the unexpectedness of seizures, the lack of control of their own body, and the stigmatizing reactions that consequently cause emotional discomfort.

Epilepsy was considered stressful by 46.6% of the patients, with consequences for the quality of their life. There were reports of difficulties at work, school, leisure, and interpersonal and conjugal relationships due to epilepsy. The majority of patients did not report other stressful situations or problems that might have been caused by factors other than the disease. This seems to indicate that feelings of lack of control in epilepsy can be generalized to other situations in life or that the condition of being sick might be the strongest source of stress. In addition, the patients could not disconnect from the fact they had epilepsy.

This study also aimed at identifying the objective relationship between perception of seizure control and depression/anxiety. The subject sees himself or herself as sick by evaluating the signs of the disease. The patient perceives his or her disease through the seizures. When the seizures, for whatever reason, decrease in intensity

or frequency, he or she feels in control of the disease, even if from the medical perspective, the disease is not considered controlled. The relationship of perception of seizure control to anxiety and depression, independently, was *highly significant*. It is this perception that starts the psychological process.

There is a difference between frequency of seizures (real number expressed in days, months, and years according to medical evaluation) and perception of control of seizures (subjective evaluation of seizure control) [38]. The frequency of seizures was associated with anxiety only when the seizures were *less* controlled. Goldstein and Harden [39] observed the opposite relationship: lower anxiety and high seizure frequency. There may be a mechanism of adaptation to stressful situations according to Goldstein and Harden [39], but in individuals who have learned to adapt through their lifetime. Our data show that there is a relationship between seizures and perception of anticipation of fear and uncontrolled situations.

The frequency of seizures has the meaning that the person gives to it. Self-evaluation of what it means to be sick, to have seizures, to use drugs, and to control one's seizures are parameters of well-being [25,40]. Meador [29] has stated that the perception patients have about their condition affects their quality of life more than the condition itself.

Kanner [41] calls attention to the study of the psychological processes used by patients before they began to have seizures, referring to the learning of negative cognitive interpretations and unadapted behavioral responses to stressful situations. In facing a chronic disease such as epilepsy, the attribution of negative meaning can lead to negative feelings and depression reactions [42], as well as anxiety due to the feeling of personal vulnerability [3].

When one speaks about the psychological process one can understand how complex the relationship among depression, anxiety, and epilepsy is because it activates intrapsychic variables linked to subjective interpretations that modulate and maintain the dysfunctional emotions, regardless of their origin.

The interpretative distortions are present when an arbitrary inference appears, such as "people don't accept me because I am epileptic." Many times the person with epilepsy reaches this conclusion in the absence of sufficient evidence. This is reinforced by his or her disqualifying feeling, "I am not capable, I am different from the others," together with a learned perception of rejection as Scambler and Hopkins demonstrate [43].

The perception of oneself as inept and abandoned [1] results in a series of personal difficulties and the perception of interpersonal reactions as without control, leading to what is called psychosocial stress. Gramstad et al. [44] have also shown that negativism and low perception of self-efficacy are important predictors of emotional adjustment and quality of life.

Noticing that events are controlled by external factors more than by personal influence is a central problem in adults with epilepsy [25,26,28], causing anxiety and depres-

sion. In addition, the occurrence of seizures as well as the psychosocial problems triggered by epilepsy can lead to the development of an external locus of control. These patients evaluate themselves as having little control over the basic events of life, which causes intensification of the chronic anxiety and depression.

People who feel in control of the stressful events of life usually have fewer health problems [45]. How people face their disease is not directly related to the severity of the seizures [40], but to the strategies through which they define their personal and social reality [46]. After evaluation of a situation as stressful, the tendency to choose certain strategies depends on the individual's repertoire and experiences reinforced through his or her lifetime.

More adaptive strategies emerged, such as searching for social support, medical treatment, and spiritual help. Seeking physical support was a way to deal with seizures when they happened. Nonacceptance and difficulty in speaking about the disease decrease a person's chances to be successful and accepted and decrease the possibility of academic, professional, and interpersonal development. Emotional development is also affected, predisposing to the occurrence of affective disorders [47]. Withdrawal and nonconfrontational behavior may reinforce self-criticism, self-rejection, and internal stigma.

These strategies can be very powerful in that they can help those with a chronic condition maintain acceptable levels of well-being [48]. Confrontational and positive attitudes toward life are associated with a better prognosis, satisfaction, and well-being. Social support is one strategy used by individuals to cope with the disease and is fundamental in reducing the impact of the stressor [17].

This study has demonstrated the occurrence of psychiatric comorbidity, the burden of living with epilepsy, and the importance of the subjective variables involved in epilepsy. Anxiety and depression are separate psychiatric conditions that are often related, according to Cramer et al. [49] and Johnson et al. [50]. We also noted the strong association between anxiety and depression. In addition, the relative power of these symptoms compared with demographic and clinical epilepsy variables (e.g., seizure frequency, severity, and chronicity) was verified and reinforces the data obtained in our study.

The impact of epilepsy extends beyond the seizure experience, involving evaluation of the patient's current reality [51] as well, where subjective factors are linked to external factors and have a fundamental role in leading to comfort and emotional well-being.

This study showed the importance of cognitive aspects in the control of emotional behavior in chronic diseases. It seems evident that anxiety and depression are the consequences of the relationship between patients and the way they manage their lives. Psychological techniques, including self-control, psychophysiological methods, and other cognitive techniques have been efficient in the control of anxiety and depression and in the improvement of psychosocial adjustment of patients with epilepsy [52,53].

The open-ended questions in the interview were aimed at supporting the psychological discussion of the data related to the association of perception of seizure control to anxiety and depression. These data were qualitatively analyzed after they had been categorized. The importance of this study is that it shows the psychological process involved in the disease. In future research, scales or protocols will allow more objective analyses about the actual beliefs and experiences of this population and their relationship to depression and anxiety.

5. Conclusion

Several studies tend to support the association between epilepsy and psychological risks and its relationship to well-being and adjustment. Our knowledge of the behavior of the patient with epilepsy is incomplete. There remain many questions related to the psychological variables and their connection to organic variables.

To understand the determinants of adaptation, it is important to develop a paradigm in which interactive models incorporate biomedical and psychological variables. Certain factors seem to be more closely related to anxiety and depression than others, but it is important to determine the causal relationships or covariation of the interaction of these factors in future research.

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