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# Positive Psychosocial Variables and Outcome Variables in Persons with Epilepsy

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## 1. Introduction

Epilepsy is a chronic disease and the world's most common serious neurological disorder (International League Against Epilepsy [ILAE], 2003a; Jacoby, 2002). Epilepsy is the name for a group of functional disorders of the brain, characterised by repetitive seizures, caused by abnormal, excessive electric discharges of the nerve cells or neurones in the brain (ILAE, 2003b). Between 5% (ILAE, 2003b) and 11% of the population experience at least one seizure at some point (Hauser & Hesdorffer, 1990), but not everybody who experiences an epileptic seizure will develop epilepsy. A diagnosis of epilepsy requires that the patient has had a minimum of two unprovoked seizures (ILAE, 2003b).

Nowadays, the new generation of antiepileptic drugs and treatment adherence (i.e., proper use of pharmacological agents and compliance to life style orientations) guarantee that the majority of patients do not have seizures and can maintain a normal life, with a low cognitive and aesthetic impact of the disease. Nevertheless, epilepsy therapy may be prolonged and a cure not always attainable.

The prognosis for seizure control is very good, and with appropriate therapy approximately 75% of patients with epilepsy become seizure free (ILAE, 2003a). Epilepsy is, nonetheless, a chronic disease, i.e., a disorder that persists for an extended period and affects a person's ability to function normally. Seizure control (caused by pharmacological treatment or surgery, for instance) does not necessarily mean absence of epilepsy.

The impact of epilepsy may be greater than that of some other chronic conditions, partly because of the unpredictability of seizures, and partly because of the associated stigma. In fact, research indicates that seizure disorders are often associated with a variety of psychological and social problems, as well as malaise (Collings, 1990, 1995; Jacoby et al., 1996) and social and political isolation. Thus, as any other chronic illness, epilepsy has the potential to induce profound changes in a person's life, resulting in negative effects on quality of life (QOL) and wellbeing (de Ridder et al., 2008).

In this context, improvement of the psychosocial health of people with epilepsy is a relevant issue for researchers and clinicians, making it important to understand psychosocial dimensions associated with the disease that facilitate epilepsy patients' adjustment. Psychosocial health depends on adjustment to epilepsy. It is a process that has a start and an end point: it can be assessed by the results, or as an end point, and can be viewed by its positive side (positive adjustment) and not as an adjustment disorder.

## 2. Adjustment to chronic disease

What does it mean to adjust to a chronic disease? The literature suggests three main conclusions: (a) a chronic disease requires adjustment across multiple life domains, (b) adjustment unfolds over time, and (c) there is marked heterogeneity across individuals in how they adjust to chronic disease.

Adjustment is a process that begins at the presentation of symptoms and continues throughout the course of the illness and responds to changes in illness status (Sharp & Curran, 2006). It can be defined as a response to a change in the environment that allows an organism to become more suitably adapted to that change (Sharpe & Curran, 2006). It refers to the healthy rebalancing by patients to their new circumstances (de Ridder et al., 2008). However, for about 30% of patients, the adjustment phase is prolonged and sometimes unsuccessful (de Ridder et al., 2008). The above definition implies that adjustment occurs over time, and often refers to a desirable state or endpoint. de Ridder et al. (2008) and Stanton et al. (2007) report key elements of successful adjustment to a chronic illness: (a) the successful performance of adaptive tasks (e.g., adjustment to disability, maintained emotional balance, and preservation of healthy relationships); (b) the absence of psychological disorders; (c) the presence of low negative affect and high positive affect; (d) adequate functional (e.g., work) status; (e) and the satisfaction and wellbeing in various life domains.

Several models have been proposed on how patients could achieve these outcomes, namely (de Ridder et al., 2008): the model of cognitive adaptation, which emphasises illness acceptance and perceptions of control over illness; the personality model that emphasises the role of personality factors in adjustment; and the stress and coping model that emphasises strategies used by patients to deal with adaptive tasks imposed by disease. All the models presuppose relationships between different kinds of psychosocial and behavioural variables.

In other words, the adjustment process includes contextual, disease, and personal characteristics, more stable (like personality) or more elusive (more easily influenced by training or education, like stigma perception, coping, positive psychological state, adherence to treatment, social support, psychosomatic symptoms, spiritual beliefs, and life events), and their conjoint impact on outcome variables (health status perception, health related quality of life - HRQOL -, and subjective happiness).

In this context, the objective of the present study is to discuss the role of psychosocial variables in adjustment to everyday life in persons with epilepsy.

## 3. Adjustment challenges

When adjustment is unsuccessful, mental health problems/personality disorders may become (more) evident or more intense. Inversely, these situations can make adjustment more difficult. One should, nevertheless, bear in mind that what can be seen as a personality trait may, in fact, be an attempt to compensate deficits, namely, cognitive deficits (Devinsky & Najjar, 1999; Hermann & Whitman, 1984; Perrine & Kiolbasa, 1999). It is also worth stressing that the concept of epileptic personality has become, a long time ago, obsolete, since only a part of patients is at risk of developing characteristic personality traits (that present themselves in a highly variable degree) (Blumer, 1991, 1999). However, some epileptic patients present “strange” personalities that do not fulfill the criteria for specific psychiatric disorders (Perrine & Kiolbasa, 1999).

In this context, timing may be a crucial element. In fact, research data suggest that epilepsy onset in adolescence influences the development of adult personality traits: patients with epilepsy onset during adolescence had higher neuroticism compared with normative data and other patients; high neuroticism, particularly when accompanied by lower extraversion, predisposed to poor adjustment to chronic epilepsy as reflected by impaired mood and difficulties with family functioning (Wilson et al., 2009).

But even when psychological and psychosomatic symptoms are absent, and the patient is successfully adjusting to living with epilepsy, there are no guaranties that significant others will not have difficulty adjusting to the situation. In fact, epilepsy has a significant impact on both the physical and psychological functioning of family members and other informal carers (Lee et al., 2002). Behrouzian and Neamatpour (2010), for example, report that the prevalence of symptoms of depression and anxiety was increased in mothers of epilepsy patients.

### **3.1 Psychological/psychiatric symptoms**

Research suggests that personality traits or psychiatric presentation of patients with epilepsy have special features, resulting in a higher prevalence of psychiatric diagnoses, such as depression and psychosis, when compared with the general population (Locke et al., 2010). Vuilleumier and Jallon (1998) report that the overall prevalence of psychiatric disturbances in epileptic patients can be estimated between 20 and 30 per cent, with psychotic disorders, depression, and suicide as the three most common among interictal disturbances. An epidemiological study with 36,984 subjects, aiming to explore numerous aspects of mental health in persons with epilepsy in the community, compared with those without epilepsy, found an increased prevalence of mental health disorders, including a higher prevalence of suicidal ideation, when compared with the general population (Tellez-Zenteno et al., 2007). However, data about psychiatric disorders associated with epilepsy are heterogeneous with great variability and discordance in results encountered in epidemiologic studies.

Psychiatric disturbances correlate positively with the multiplicity of seizures but often inversely with their frequency. The overall risk might be the highest during the first years after diagnosis of epilepsy, as well as in patients with temporal lobe foci, previous depression, or psychosis. In a study with 2152 persons with epilepsy in Norway, Naess, et al. (2007) found that seizure frequency, medication side effects, and co-morbidity are strongly related to self-reported psychological distress. In another study, comparing people with intellectual disability and epilepsy with people with intellectual disability and no epilepsy, Arshad et al. (2011) found that rates of mental health problems, including those in the schizophrenia spectrum, personality and anxiety disorders, were significantly lower among patients with epilepsy.

Depressive disorders are the most common type of psychiatric co-morbidity in patients with epilepsy: they have various clinical presentations, some typical of the different types of mood disorders in non-epileptic patients, others constituting rather frequent atypical presentations that can easily go unrecognized (Kanner & Balabanov, 2002). The prevalence of anxiety symptoms is also higher in patients with epilepsy than in the general population or with other chronic medical disorders (Beyenburg et al., 2005).

Studying anxiety and depression in persons with epilepsy, Meneses et al. (2008), Pais-Ribeiro et al. (2007), and Trueman and Duthie (1998) found that patients reported having

both anxiety and depression levels characterised as mild, moderate and severe, although comparisons with other groups of persons with other chronic diseases, or no disease, showed lower levels of anxiety and depression.

### 3.2 Psychosomatic symptoms

Unsuccessful adjustment may also be accompanied by psychosomatic symptoms. “The psychosomatic symptom (PS) remains without an aetiological explanation, albeit the innumerable studies from diverse areas of biological and psychological knowledge” (Salim, 2007, p. 234). Consequently, Salim presents a review of the psychoanalytic theory of the PS and other lines of thought central to his aim: “to present the hypothesis that the etiology of the PS has a relationship with traumatic recurrence and autistic withdrawal”, both of which are “instinctive biological responses to soothe and prolong life” (2007, p. 234). He finishes his article stressing the need to develop more studies involving psychoanalysts, psychiatrists and neuroscientists” (Salim, 2007, p. 238).

In this context, Nagane et al. (2009) investigated individual variation in the levels of growth hormone in healthy students (21-22 years) and had them rate their psychosomatic symptoms, with a self-assessment questionnaire (five items pertaining to physical symptoms – drowsiness, poor appetite, heaviness in the head, dizziness, whole-body fatigue - and five to mental symptoms - lack of motivation, easily irritated, feelings of melancholy, desire to rest, anxiety), twice a day. They concluded that “psychosomatic symptoms may be associated with circadian dysfunction, as inferred from blunted rhythmicity in growth hormone secretion”.

In a more recent study, Åslund et al. (2010) asked students between 13-18 years old how often they suffered from: headache, stomach ache, feelings of nervousness, feelings of irritation, and sleep problems, as a mean to assess their psychosomatic symptoms. Based on the answers, 6.4% of the boys and 20.4% of the girls were classified as having many psychosomatic symptoms; girls reported more psychosomatic symptoms; individuals within the group with low neighbourhood social capital had approximately double the odds of having many psychosomatic symptoms compared with those with high neighbourhood social capital, while individuals within the group with low general social trust had a more than a three times increased odds of having many psychosomatic symptoms compared with the group with high general social trust; parental unemployment and low subjective SES were also related to psychosomatic symptoms.

Consequently, it is surprising to verify that, although psychosomatic symptoms have been studied for so long, there are fewer articles than could be expected on the psychosomatic symptoms of individuals with epilepsy, suggesting that the scientific community hasn't been very interested in analyzing them.

### 3.3 Stigma perception

Dell (1986) defined stigma as a distinctive feature in an individual and the devaluation society places on that difference. Stigmatisation is most effective if the stigmatised person holds the same belief as the society, as it often occurs in people with epilepsy. Despite the important actual clinical and therapeutic progress, people with epilepsy continue to suffer from discrimination (ILAE, 2003d). In fact, epilepsy is often surrounded by prejudice and myth, which can be overcome only with enormous difficulties (Austin et al., 2004).

These difficulties can be even greater in some developmental periods. For instance, in adolescents with epilepsy, stigma is a complex concept to investigate because it involves



personal attitudes and beliefs, elements of secrecy and disclosure management, and influences from the social environment (Austin et al., 2004). It is widely expected that reducing stigma should help adolescents (and older patients) with epilepsy experience an improved QOL (Austin et al., 2002).

In fact, DiIorio et al. (2003) found that participants reporting higher levels of perceived stigma also reported lower levels of self-efficacy to manage epilepsy, more negative outcome expectancies related to treatment and seizures, lower levels of medication management, medication adherence, and patient satisfaction, greater management of information related to seizures. They also found that other demographic and disease variables, like income, age at first seizure, seizures during the past year, lower self-efficacy, negative outcome expectancies for seizures, and satisfaction explained important variance in perceived stigma. Stigma was also associated with interactions of seizure worry and employment status, self-efficacy and social support, and quality care and age at seizure onset (Smith et al., 2009) and predicted depressive symptoms at baseline, 3 months, and 6 months (Reisinger & DiIorio, 2009), as well as QOL at a later time (Whatley et al., 2010).

As a result, stigma-reducing interventions focused on individuals with epilepsy probably reduce epilepsy's health burden and decrease the emotional impact of epilepsy (Birbeck, 2006).

Research found that there are cross-cultural significant differences in stigma perception between patients from European countries (Baker et al., 1999). Baker (2002) report that the factors that best predict epilepsy stigma are seizure frequency, knowledge of epilepsy, duration of epilepsy, and seizure type.

All that has been said so far underscores the importance of knowing the (psychosocial) variables associated to successful adjustment. In fact, variables like hope, optimism, and spirituality are among the positive variables useful to consider when organizing programs to help patients adjust to a life with disease.

## **4. Adjustment and psychosocial variables**

### **4.1 Hope**

Hope is defined as the perceived capability to derive Pathways to desired goals, and motivate oneself via Agency thinking to use those pathways (Snyder, 2002). The hope construct includes agency thoughts that "tape the perceived capacity to initiate (causal capacity) and sustain (agentic capacity and action-control beliefs) movement toward desired goals" (Little et al., 2006, p. 72).

Rustøen et al. (2005) found that hope scores differed significantly between hospitalized heart failure patients and the general population (for 7 of the 12 items and global score), being that patients reported higher (better) hope. Hope was associated with patients' level of satisfaction and number of associated comorbid diseases, and was predicted by self-assessment of health and satisfaction with life.

In another study, patients with end stage renal disease identified hope as central to the process of advance care planning: it helped them determine future goals of care and provided insight into the benefits of advance care planning and their willingness to engage in end of life discussions (Davison & Simpson, 2006).

Additionally, research suggests that people with higher levels of hope cope with disease more effectively (Chi, 2007; Elliott et al., 1991; Snyder, 2002). Nonetheless, research on patients' hope (namely, epileptic patients) is not easy to find (cf. Lohne, 2001).

## 4.2 Optimism

Optimism is a global generalized tendency to believe that one will usually experience good versus bad outcomes in life (Scheier & Carver, 1985, 1992). Research asserts that optimism and pessimism strongly influence physical health and help people cope with chronic diseases (Aspinwall et al., 2001; Ebert et al., 2002; Scheier & Carver, 1992).

In a sample of general medical outpatients, a pessimistic explanatory style (Optimism-Pessimism scale of the Minnesota Multiphasic Personality Inventory) was significantly associated with a self-report of poorer physical and mental functioning (SF-36) 30 years later; scores on all 8 health domains were significantly poorer in the pessimistic group than in both the optimistic and the mixed group (Maruta et al., 2002). Moreover, it is believed that optimism can serve as a protective factor when facing difficulties in life such as illness (Fournier et al., 2002; Giltay et al., 2004, 2006).

The same happens with epilepsy: Pais-Ribeiro et al. (2007) found that optimism is the variable that best contributes to mental health status perception and QOL in persons with epilepsy. It was found that: (a) optimism/pessimism are strong predictors of QOL; (b) optimism/pessimism do not predict objective health (assessed by the objective physical disability rating scale); (c) optimism does not have a stronger effect on objective health or QOL for one diagnostic group relative to the other (right temporal lobe epilepsy, left temporal lobe epilepsy, psychogenic non-epileptic seizures) (Kent, 2008); (d) explanatory style (i.e., optimistic explanations for negative events are attributed to external causes that temporarily affect specific domains of one's life) are not good predictors of seizure load in individuals with temporal lobe epilepsy (Donnelly, 2010); and (e) in adults with intractable epileptic seizures and psychogenic nonepileptic seizures, both optimism and pessimism are good predictors of seizure group, and attributional style is an index of personality and cognitive response to stress (Griffith, 2008). Nevertheless, optimism seems an under-recognised variable in the context of epilepsy research.

## 4.3 Self-efficacy

Self-efficacy or “efficacy expectation is the conviction that one can successfully execute the behaviour required to produce the outcomes” (Bandura, 1977, p. 193), predicting “with considerable accuracy the level of performance” (Bandura & Adams, 1977, pp. 303-304). I.e., “given appropriate skills and adequate incentives... efficacy expectations are a major determinant of people's choice of activities, how much effort they will expend, and of how long they will sustain effort in dealing with stressful situations” (Bandura, 1977, p. 194).

Being so, this variable has been occupying a central place on Health Psychology (Ribeiro, n.d.). In epilepsy research, the development of an instrument to measure self-efficacy in persons with epilepsy, based on Bandura's self-efficacy theory (Dilorio et al., 1992), would suggest this context presents no exception. Furthermore, considering the concept's definition, one would expect studies on self-efficacy to increase in the context of the Positive Psychology movement. But this does not seem to be the case.

Be as it may, research has showed that self-efficacy (in epilepsy) correlates or predicts social support, self-management, lifestyle management, depressive symptoms, and QOL (Amir et al., 1999; Begley et al., 2010; Dilorio et al., 1992; Lee et al., 2010; Robinson et al., 2008). Additionally, self-management, depressive symptoms, and seizure severity predict self-reported epilepsy self-efficacy, as do patient satisfaction and stigma, while social support and regimen-specific support do not (Dilorio et al., 2006).

Moreover, improvements in (seizure) self-efficacy of individuals with epilepsy can be obtained with interventions like WebEase, an Internet-based self-management program (DiLorio et al., 2009), and even with an educational intervention without a psychological component (Frizzell et al., 2011).

#### 4.4 Social support

Social support can be defined as the existence or availability of individuals in whom we can trust, that show us they care about us, value us, and like us (Sarason et al., 1983). Nevertheless, there is no consensus on its definition, since there are numerous ways to characterize/classify the social domain (Berkman, 1984; Bruhn & Philips, 1984; Cassel, 1976; Cobb, 1976; Cohen, 1988; Kaplan et al., 1977; Taylor, 1990), and several types/dimensions of social support (Cohen & McKay, 1984; Cramer et al., 1997; Dunst & Trivette, 1990; Singer & Lord, 1984; Weiss, 1974). Researchers tend, however, to agree on the multidimensionality of social support and that its different aspects have diverse effects on individuals or groups (e.g., Ridder & Schreurs, 1996).

Even though the process is not clear (Pais-Ribeiro, 1999), the strong relation between social support and numerous health/disease indicators is very robust (Broadhead et al., 1983; Ell et al., 1992; Hanson et al., 1989; Kessler et al., 1985; Ornelas, 1996; Rutter & Quine, 1996; Schwarzer & Leppin, 1989, 1991; Thomason et al., 1996; Wethington & Kessler, 1986).

In epilepsy patients, social support is related to/predicts: self-rated health status, life satisfaction (Elliott et al., 2011), depressive symptoms (Lee et al., 2010; Reisinger & DiLorio, 2009; Robinson et al., 2008), self-management (Begley et al., 2010), and QOL (Amir et al., 1999; Choi-Kwon et al., 2003; Whatley et al., 2010). Social support is also a mediator between disease severity and mastery (Amir et al., 1999).

Consequently, it is not surprising that researchers defend that clinicians should encourage epilepsy patients to improve their social support (e.g., Elliott et al., 2011), developing programs that improve it (e.g., DiLorio et al., 2009).

#### 4.5 Spiritual beliefs

Spirituality, namely spiritual beliefs, has been increasingly considered when caring for and studying chronic patients (cf. Meneses, 2006). Among all the theoretical contradictions (Hill & Pargament, 2003; Miller & Thoresen, 2003), one thing is certain - spirituality and religiosity are not interchangeable: spirituality implies "a polyhedron-like relation with the transcendent that can be experienced through religiosity and its expressions (doctrinal, celebrative and/or moral-behavioural) or through occurrences associated with art, philosophy, nature, etc." (Valiente-Barroso & García-García, 2010, p. 226).

Similarly, Koenig et al. (2001, as cited in Moreira-Almeida & Koenig, 2006, p. 844) argue that religion "is an organized system of beliefs, practices, rituals, and symbols designed to facilitate closeness to the sacred or transcendent (God, higher power, or ultimate truth/reality)", while spirituality "is the personal quest for understanding answers to ultimate questions about life, about meaning, and about relationship with the sacred or transcendent, which may (or may not) lead to or arise from the development of religious rituals and the formation of community".

Gardner (2001, as cited in Valiente-Barroso & García-García, 2010, p. 226) refers to a "spiritual intelligence", an ability included in the "existential intelligence", i.e., "the ability to place oneself in relation with the cosmos, and in relation with existential traces of the



human condition, like the meaning of life, the meaning of death, interpersonal love or the artistic experience". In this context, Emmons et al. (1998, as cited in Valiente-Barroso & García-García, 2010, p. 227) present a list of abilities of the spiritual intelligence: transcendence, ability to reach enlightened consciousness states (mystic experience regarding the sacred), ability to give significance to the activities and events with a sense of sacred, ability to reuse spiritual resources to solve life problems, and ability to behave in a virtuous manner".

In the past decades spirituality has caught the attention of organizations like the World Health Organization and various spirituality indicators have been analyzed in diverse populations, namely those outside the healthcare system (e.g., Panzini et al., 2011). In university students, for instance, it was found that: (a) reports were very heterogeneous; (b) those with religion reported higher Connectedness to a spiritual being or force, Spiritual strength and Faith; (c) those without health problems reported higher Inner peace/serenity/harmony; (d) longer duration of health problems was related to higher Awe, Wholeness & integration, Spiritual strength, Inner peace/serenity/harmony, and Hope & optimism, stressing the need for longitudinal studies to clarify the role Inner peace/serenity/harmony has throughout the course of disease; (e) spirituality was related to QOL (Meneses et al., 2010a, 2010b). Nurses' spiritual well-being was found to be globally positive, with most nurses referring it was important to offer patients spiritual assistance, even though most had no training (undergraduate, graduate or other Nursing courses) to give spiritual assistance (Pedrão & Beresin, 2010).

In fact, spirituality seems to play an important role in the QOL, health, disease (progression) and even cure (p.e., Chattopadhyay, 2007; Gallagher et al., 2002; Koenig, 2000, 2004; Mueller et al., 2001; Pais-Ribeiro et al., 2004; Post et al., 2000; Rippentrop, 2005; Seawaerd, 2000; Tate & Forchheimer, 2002), and religious needs assessments, as well as spiritually focused therapy may positively impact illness adjustment (Lavery & O'Hea, 2010). There have been, nevertheless, plenty of contradictory data, whose meaning remains uncertain (cf. Powell et al., 2003; Rippentrop, 2005). Some even question if spirituality can, or should, be scientifically studied (Miller & Thoresen, 2003).

When searching for research reports on epilepsy patients' spiritual beliefs, one essentially finds studies on complementary/traditional/alternative healing methods (e.g., traditional spiritual healing), not always regarding epilepsy, even though many go beyond epilepsy patients (Azaizeh et al., 2010; Coleman et al., 2002; Ismail et al., 2005; Shaikh & Hatcher, 2005; Winkler et al., 2010).

Valiente-Barroso and García-García (2010), reviewing some of the phenomena regarding altered consciousness states associated with spirituality, in order to clarify its neurological basis, focused on some forms of epilepsy related to religious spirituality and on mystic states due to hallucinogens. They argued that "regarding the interictal spiritual phenomenology, one should consider not only the underlying neurological mechanisms, but also the influence of psychosocial factors in order to gain a deeper understanding of this phenomenon" (Valiente-Barroso & García-García, 2010, p. 230).

Giovagnoli et al. (2009) explored the role of spirituality (defining it as the complex of personal transcendence, connectedness, purpose, and values) in determining QOL in chronic neurological disorders (epilepsy, brain tumors, ischemic or immune-mediate brain damage), comparing patients with healthy controls. Patients reported worse QOL, with no difference between the patient subgroups. Mood, Cognition, Inner Energy, schooling, and subjective health status correlated with QOL, but only Mood and Inner Energy predicted QOL.

In another study, QOL indicators of focal epilepsy patients were significantly predicted by spiritual (namely, Awe and Transcendence), mood, and cognition factors, highlighting the contribution of spirituality to QOL in epilepsy (Giovagnoli et al., 2006).

#### 4.6 Coping

A recurrent construct seems to be coping, since it is through it that several variables “operate”. For instance, life events (e.g., a chronic diagnosis) may have a smaller impact on an individual (e.g., on his/her QOL) if s/he is able to use adequate coping resources/strategies. Additionally, conceptualizing religious coping multidimensionally, one might find a negative relationship between negative religious coping and illness adjustment (Lavery & O’Hea, 2010).

Having seizures and/or taking care of someone with seizures can be a challenge for an individual personal coping style, i.e., “person’s typical response when dealing with stressful life-events or smaller problems in daily life” (Westerhuis et al., 2011, p. 37). In fact, research has shown that partial epilepsy patients used mainly palliative reaction patterns, active confronting, and avoidance; the prevalence of their coping styles differed from the coping styles of the reference Dutch population; and a passive coping style predicted QOL (Westerhuis et al., 2011).

According to the Turkish version of the Ways of Coping Inventory, and to a two dimensional coping styles – problem-focused efficient ways of coping (self-confidence, optimism, seeking social support) and emotion-focused inefficient ways of coping (submissiveness, helplessness), adolescents with epilepsy had lower self-confidence and overall lower problem-focused ways of coping than controls; lower self-esteem and emotion-focused coping and higher self-esteem and problem-focused ways of coping were associated; those with higher total problem behaviors also had lower problem-focused ways of coping (Çengel-Kültür et al., 2009).

Piazzini et al. (2007) also found differences in coping responses, but between other samples: drug-resistant patients seemed to adopt the “denial” and the “exclusion” strategies more, while seizure-free subjects used the “control” strategy more; and “control” was associated with better social adaptation.

Furthermore, patients with refractory epilepsy tend to present themselves in a clinical encounter with a neurologist as resourceful and in control of their condition, but analyzing subtle linguistic and interactional features it becomes clear that some find their disorder quite difficult to cope with (Monzoni & Reuber, 2009).

The same can be said of epilepsy patients’ families, since a child’s illness is a critical event that places additional stress and burden on families (McCubbin & Patterson, 1983, as cited in Modi, 2009). Parents of children with new-onset epilepsy reported the highest levels of stress regarding finances, disciplining their child with epilepsy, concerns about education, and their marital relationships, but no significant differences were found between patients’ parents and controls (without epilepsy) on parenting stress (Modi, 2009). In another sample, mothers’ coping profiles were not correlated with the adolescents’ and there were no significant differences between the coping profiles of mothers of the epilepsy and the control group (Çengel-Kültür et al., 2009).

Be as it may, given that parental coping may have a negative effect on the child’s adjustment to disease, and that stress is a frequent precipitant of seizures, it is essential to identify ways to facilitate parents’ and patients’ positive coping skills (Arida et al., 2009; Duffy, 2011).

Exercise can be a powerful strategy among stress reduction therapies for the treatment of seizures (Arida et al., 2009). Moreover, the Coping Openly and Personally with Epilepsy (COPE), an intervention based on cognitive-behavioral techniques and focused on epilepsy education, primary and secondary coping skills, was considered, by caregivers and youth with epilepsy, as highly satisfying, and promising in terms of feasibility and accuracy (Wagner et al., 2011).

#### 4.7 Treatment adherence

The first problem one faces when considering treatment adherence is concept definition. In fact, compliance may be defined as to “obey, submit, defer or accede to instructions” (Donovan & Blake, 1992, as cited in Eatock & Baker, 2007, p. 117); adherence as “what is expected of the patient as opposed to compliance being told what to do” (Barofsky, 1978, as cited in Eatock & Baker, 2007, p. 118), involving more co-operation and agreement; and concordance as advocating “a decision-making process where patients can feel more comfortable with their treatment” (Marinker & Shaw 2003, as cited in Eatock & Baker, 2007, p. 118).

Non-adherence to medication encompasses taking too few doses, too large a dose, too many tablets, or at the wrong time, accidentally (through forgetfulness, misunderstanding, or uncertainty about clinician’s recommendations) or intentionally (due to expectations of treatment, side-effects, and lifestyle choice), which has implications for intervention (Eatock & Baker, 2007).

To make matters worse, the three concepts can encompass not only medication but also lifestyle changes that have been recommended to promote health. In effect, a larger proportion of adults with epilepsy reported higher self-efficacy for medication management behaviors than for healthful lifestyle behaviors (Kobau & DiIorio, 2003).

A second problem has to do with assessment, since the constructs in question have been measured in different ways, each of which with important limitations (Eatock & Baker, 2007). This heterogeneity may be one of the causes of divergence in research results, namely those concerning factors associated with better/worse adherence, but it is certainly not the only one.

Briesacher et al. (2008), for instance, found modest variation in the adherence to newly started drug therapies in privately insured adults. They also found that adherence improved across seven different diseases, except seizure disorders, with increasing age and that add-on therapy and a history of trying other drugs for the condition before starting the new therapy improved adherence in association with seizure disorders, but not all the other conditions.

Others have found that co-morbid chronic disease, self-driving, seizure after a missed dose, and self-efficacy are significantly associated with medication compliance (Chen et al., 2010). Non-compliance with the pharmacological treatment was also associated with: lack of money to buy the medicine, patient's failure to acknowledge the disease, poor response to treatment, belief that the treatment was useless, and factors associated with the relationship between physician and patient (Enríquez-Cáceres & Soto-Santillana, 2006). Moreover, treatment adherence was negatively associated with the presence of adverse effects and correlated with better QOL (Martins et al., 2009). Additionally, certain medications convey differential risks of poor adherence in patients with epilepsy (Zeber et al., 2010).

Since medication adherence is critical to prevent/minimize seizures and their impact on patients’/families’ QOL, researchers have been trying to identify factors (e.g., psychological

characteristics, drug regime, family support, impact on everyday life, relationship with the clinician) that predict (non-)adherence and interventions that promote adherence (Eatock & Baker, 2007).

Even though the aim of WebEase, a multicomponent, interactive, Internet-based self-management program, is “to encourage people with epilepsy to take their medications as prescribed, practice strategies to reduce stress and adopt strategies to facilitate adequate sleep” (DiIorio et al., 2009, p. 186), for most measures, but not all, there were no statistically significant gains. In epilepsy self-management and one measure of adherence there were, nonetheless, improvements.

Some other interventions (e.g., intensive reminders and “implementation intention”) have potential to improve adherence to antiepileptic medications, but additional evidence on their efficacy is needed (Al-Aqeel & Al-Sabhan, 2011). “What is increasingly clear... is that total adherence is an unrealistic goal” (Eatock & Baker, 2007, p. 129).

## 5. Adjustment and outcome variables

### 5.1 Health status perception

Ross (2010), as other authors before her, presents health as a complex construct, with several dimensions, arguing that “perception influences health status and how people responded to policy interventions and other solutions” and that self-reported health status and objective health status are “outcomes of the socio-economic and behavioral situation of the individual” (Ross, 2010, p. 10). In addition, she refers that “it is expected that these two measures, objective and subjective, will reinforce each other to create a single health status perception for an individual.... Unfortunately, there is evidence that this is not always the case, which leads to the gap between perception and reality” (Ross, 2010, pp. 4-5). Nevertheless, “the perception of health status by the individual is a more significant indicator than clinical indicators. Researchers use this indicator to understand the value the individual assigns to health” (Bordoni et al., 2006, p. 68).

In practice, subjective health status is measured by an individual’s self-reported health status, and objective health status is defined by visible health metrics (i.e., health characteristics that provide sensory feedback to individuals - fever, rash, increased waist measurement, etc.) and technical health metrics (which tend not to provide overt feedback/to be asymptomatic) (Ross, 2010, p. 5).

To make matters worse, self-reported health status is “the result of a complex aggregation process, involving information and weights known only to the individual, consciously and sub-consciously” (Ross, 2010, p. 4). Consequently, “measuring health status is a complex process that requires the use of indicators that evaluate health both in terms of disease and of the impact the health-disease- care process has on the quality of life” (Bordoni et al., 2006, p. 68).

Li et al. (2007) present part of the Phase VI of the Demonstration Project (DP) on Epilepsy, part of the Global Campaign Epilepsy Out of the Shadows-WHO-ILAE-IBE in Brazil, with a mean follow-up of 26 months (1-38). They report a model of epilepsy treatment at primary health level with which people with epilepsy can be treated with important reductions in seizure frequency and other improvements: the opinions of patients, relatives, and physicians regarding the overall health status at the end of the DP were similar and indicate considerable improvements.



In adults with epilepsy receiving antiepileptic drugs for treatment, Perucca et al. (2009) tried to identify patterns of association of adverse effects and their relationships with subjective health status at baseline and over a prospective 4-month follow-up. The self-report health assessments include the Adverse Event Profile, the Quality of Life in Epilepsy Inventory-89, and the Beck Depression Inventory. Their results agree with clinical and research data: patients taking antiepileptic drugs usually report more than one adverse effect, revealing the important burden of toxicity associated with antiepileptic drugs; in patients with refractory epilepsy, adverse effects and mood disorders may be more important than seizure frequency in determining subjective health status.

Pais-Ribeiro et al. (2007) results showed that epilepsy patients' optimism was the best predictor of mental health status perception and QOL, whereas cognitive functioning perception was the best predictor of physical health status. In the same study, seizure control was a significant predictor of physical health status perception but not of mental health status perception or QOL.

I.e., there are some psychosocial variables that are associated with health in persons with a chronic disease: those variables are buffers reducing the impact of disease on health. This perspective assumes a positive health perspective. Seligman (2008) explains that positive health describes a state beyond the mere absence of disease and is definable and measurable as it is defined by the World Health Organization (a state of complete positive physical, mental, and social well-being and not merely the absence of disease or infirmity (WHO, 1948)).

Positive health acts as a buffer against chronic diseases. Positive health in general populations and in people with chronic diseases predicts longevity, quality adjusted life years and/or disability adjusted life years that individuals go on to live, less costs for health and illness among individuals in positive health, positive progression of disease and how well an individual responds to the challenges of disease, high status on the subjective, social and work functional variables.

## 5.2 (Health-related) Quality of life

QOL is recognised as a vague and ethereal entity, something that many people talk about, but which nobody knows very clearly what to do about (Pais-Ribeiro, 2004). However, QOL becomes an important primary end-point in clinical intervention (Bucher et al., 1999).

We can find many definitions. Farquhar (1995) proposes an organization of QOL definitions as: global definitions, component definitions (research-specific and non-research-specific), focused definitions (explicit or implicit), combination definitions and lay definitions.

ILAE (2003c) propose the following QOL definition: an individual's emotional response to his or her life circumstances, the gap between these circumstances and their expectations, and their ability to meet their personal needs. When considered in the health/disease field, QOL is sometimes named HRQOL and tends to include items, or domains, specific for the focused disease.

Pais-Ribeiro (2004) remembers that there is a wide disagreement about the meaning of the term "quality of life" and how to measure it. Different researchers or professionals prefer definitions and measures influenced by the preoccupations of their respective disciplines. The same happens with the diseases and clinical settings.

QOL measures tend to incorporate five broad domains: physical, occupational, psychological, social, and somatic (ILAE, 2003c).



Research suggest that there are no differences between QOL of persons with epilepsy and persons without epilepsy (Liou et al., 2005; Montanaro et al., 2004; Raty et al., 2003).

Neuropsychological variables seem to be related with QOL, with some QOL dimensions more intimately related with cognitive performance than others (Devinsky et al., 1995; Giovagnoli & Avanzini, 2000; Meneses et al., 2009; Perrine et al., 1995).

The most consistent pattern that has emerged from these inquiries is that QOL in epilepsy is a function of the interaction of factors, including clinical variables (e.g., seizure frequency, severity, illness duration, treatment side effects, and psychiatric co-morbidity), and social variables (e.g., divorce, unemployment, social stigma, family caregiver characteristics, and social support) (Ohaeri et al., 2009; Pais-Ribeiro et al., 1998).

Kendrick and Trimble (1994) report and suggest different QOL measures in epilepsy, namely: (a) The Washington Psychosocial Seizure Inventory and the Social Effects Scale; (b) The Epilepsy Surgery Inventory and the Quality of Life in Epilepsy with 31 items (QOLIE-31); (c) The Liverpool QOL Battery.

To improve the QOL of people with epilepsy it is important to educate, not only the people with epilepsy but also the media and the general public, as well as the professionals (ILAE, 2003d).

Other positive outcomes, like subjective well-being and happiness are, in some way, similar to QOL for many experts, if not conceptually, at least in terms of assessment indicators. In a study with 2152 persons with epilepsy in Norway, Naess et al. (2007) found that seizure frequency, medication side effects, and co-morbidity are strongly related to well-being and life satisfaction.

## 6. Conclusion

Living with epilepsy (as a patient or as a patient's significant other) is challenging. The complex biopsychosocial characteristics of the condition and its treatment require adjustment. The adjustment process includes contextual, disease, and personal characteristics, and their conjoint impact on outcome variables (e.g., health status perception, HRQOL).

Scientific research and clinical practice have been showing that a number of psychosocial variables are associated with better adjustment. Unsuccessful adjustment may be accompanied (e.g., as cause or consequence) by mental health problems, personality disorders, psychological, psychiatric and/or psychosomatic symptoms, and stigma (perception).

Consequently, it is important to understand psychosocial dimensions associated with the disease that facilitate patients' adjustment and be aware of interventions that have a positive impact on adjustment. For example, several psychosocial variables and interventions are highly correlated with treatment adherence, very important for adjustment and an unquestionable concern for health care professionals. Nevertheless, research on epileptic patients' psychosocial variables, mainly positive psychosocial variables, is not always easy to find (cf., for instance, the number of articles indexed in the Pubmed database and retrievable using "epilepsy" and most of the variables mentioned in this study).

With the present study, whose aim was to discuss the role of psychosocial variables in adjustment to everyday life in persons with epilepsy, the authors hope to contribute to an area of expertise that is central to the development of comprehensive interventions aimed at epilepsy patients and their significant others, without forgetting healthcare professionals and the society as a whole.

## 7. References

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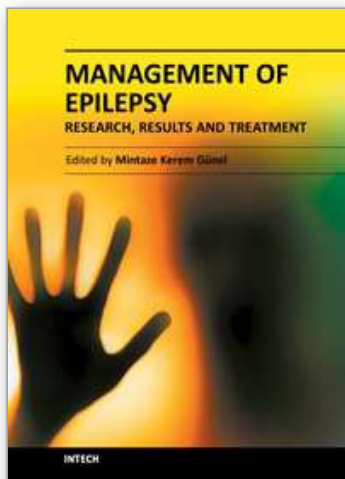
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## **Management of Epilepsy - Research, Results and Treatment**

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Epilepsy is one of the most common neurological disorders, with a prevalence of 4-10/1000. The book contains the practical methods to approaching the classification and diagnosis of epilepsy, and provides information on management. Epilepsy is a comprehensive book which guides the reader through all aspects of epilepsy, both practical and academic, covering all aspects of diagnosis and management of children with epilepsy in a clear, concise, and practical fashion. The book is organized so that it can either be read cover to cover for a comprehensive tutorial or be kept desk side as a reference to the epilepsy. Each chapter introduces a number of related epilepsy and its diagnosis, treatment and co-morbidities supported by examples. Included chapters bring together valuable materials in the form of extended clinical knowledge from practice to clinic features.

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