



## Post-traumatic stress disorder in partners of people with epilepsy

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### ABSTRACT

**Aims:** The objectives of the present study were to examine whether living with an individual who suffered from epilepsy was a potentially traumatizing event and to identify predictive risk factors in developing post-traumatic stress disorder (PTSD).

**Methods:** Six hundred fourteen respondents completed the Harvard Trauma Questionnaire, the Crisis Support Scale, the Hopkins Symptom Checklist–25, and the Dyadic Adjustment Scale. In addition, demographic variables were included in order to identify factors that might predict PTSD.

**Results:** The percentage of the participants that fulfilled the symptom criteria of PTSD was 7.7%, and an additional 43.9% reported a subclinical level of PTSD. Clinical and subclinical anxiety was unveiled in 9.3% of the respondents.

**Conclusion:** Partners were at risk of PTSD when living with a patient with epilepsy. Identified variables that explained PTSD were frequency and types of seizures medication, side effects, and objective and subjective epilepsy severity, anxiety, and depression. High level of social support decreased the level of traumatic stress.

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### 1. Introduction

Living with serious chronic illness has a direct threatening effect on the life course of healthy partners. In spite of this, most research is conducted from the point of view of patients focusing on the psychological, physical and social consequences following the illnesses, and few have studied these issues from the perspective of partners. The well-being of partners is, however, an important issue to consider, because they typically are the ones that must provide care, and become the responsible part in the relationship for maintaining overall psychological well-being, household, social relations and activities, and the financial situation. Additionally, research has shown that patients do better both mentally and physically when they receive adequate support [1]. In particular, support from spouses is considered as being the most helpful and important support for patients [1]. As such, there is an expectation of the partners being a resource for the patients. However, if the partners are going to take care of the loved ones that suffer from an illness, something or someone should also take care of them, such as public services and/or the social network. Fortunately, increasing attention is being paid to the impact of chronic illnesses on partners and also on family systems as a whole [2], which is also important in light of the fact that significant others, often, are more distressed than the patients themselves [3–5]. Some of the various consequences to partners who live with chronically ill loved ones are presented below.

Spouses of people with dementia have been shown to be some of the most vulnerable among the caregiver population, reporting

the highest depression scores. The behavioral disturbances that may follow patients with dementia, especially the uncontrollable and the unpredictable ones, seem to be responsible for increasing the stressful response in caregivers. In addition, the perception of heavy burden load and lack of social support often result in depressive and stressed feelings [6].

Spouses of patients suffering from heart failure (HF) have reported feelings of being overburdened, stressed, and depressed. Specifically, the number of caregiving tasks and the perceived difficulty in performing them have been shown to be risk factors in developing stress and the experience of burden [7]. Also, Luttik et al. [8] found that providing personal care to patients with HF and the partner's mental health were identified as more important variables to consider.

Finally, caregivers of people with multiple sclerosis (MS) have reported psychological distress in relation to caregiving. Similar to caregivers of people with dementia, the unpredictable character of this illness has also been shown to increase emotional distress [9,10].

Thus, the literature concerning psychological consequences in close relatives of people with chronic illnesses reveals that the significant others are at potential risk of developing different kinds of psychological distress. However, the role of being a caregiver of a chronically ill person is not necessarily only negative [11]. It is important to note that caregivers are willing to provide care for their loved one, and, furthermore, it is most often considered a natural, expected role [11]. Additionally, when caregivers feel involved and supported and are able to cope with the caregiver situation, this can lead to better well-being [12,13]. Furthermore, other coping strategies, such as benefit finding and attributing life events to a higher meaning, have been linked to life satisfaction in caregivers of patients with

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MS and cancer [14,15]. Yet, still, strikingly few data are available on the adaptive coping strategies of caregivers [6].

## 2. Epilepsy

Another group that experiences some of the abovementioned psychological reactions is caregivers of people with epilepsy. This caregiver population is an understudied area in the literature, in spite of the fact that epilepsy is the most frequent neurological disorder after headache [16]. In Denmark, 50,000 people suffer from epilepsy, and more than 4500 individuals are diagnosed with epilepsy every year. The prevalence is high in the first years of life, low at the ages from 20 to 50 years, and again high among elderly people. Men are more prone to develop epilepsy, except in the teenage years where women seem to dominate the picture [17]. Moreover, epilepsy is viewed as a chronic illness. A fundamental facet of epilepsy is the constant threat of sudden, unpredictable loss of control when having a seizure, because it can occur at any time with little or no warning. The seizures differ in severity and type. Some seizures are very dramatic with symptoms such as convulsions, apnea and loss of consciousness, whereas others are characterized by purposeless and strange actions, and others again appear more discrete [17].

The effects of seizures on the patient and the family depend on several factors including the type and frequency, the medication prescribed, its effects on the behavior and development of the individual, and the social impact on the patient and close relatives [18]. Specifically, the day-to-day consequences of epilepsy can consist of a change or loss of employment; an increase in spending from unexpected treatment costs; and a potential reduction in leisure activities and social interactions, productivity, and self-image. An increased incidence of sudden and unexplained death (SUDEP) is of vital concern to the patients themselves as well as their partners and other close relatives [19]. Medications are the primary means by which patients control seizures. As such, Wheless [19] found that 70% of 503 respondents with epilepsy relied solely on medication treatments to control their seizures. Moreover, of the 503 respondents with epilepsy, 87 (17%) experienced at least one seizure a week, 114 (23%) experienced at least one seizure a month, and 158 (31%) experienced less than one seizure a month; 136 (27%) had not experienced any seizures during the past year.

Co-morbidities and side effects are common in patients with epilepsy as well. Some are related to the illness itself, whereas others are related to the epilepsy treatments. Most physical effects are from the seizure medications, although memory loss, migraines, muscle twitches, and pain are associated with the illness alone [19].

Furthermore, epilepsy is associated with increased levels of depression, anxiety, poor self-esteem, and family dysfunction compared with people without the condition [20,21]. Thus, many patients with epilepsy view themselves as a burden to others because of their illness, and they feel limited in many of their daily and future activities. In addition, the illness limits many psychosocial functions, for instance, having a full-time or a part-time job and the ability to drive. As a consequence, the overall experience of quality of life (QOL) is low [19].

## 3. The psychological consequences of being a close relative of a person with epilepsy

The literature reveals that partners of patients with epilepsy are at potential risk of psychological strains. Among the variables that influence their well-being are decreased QOL, anxiety, depression, social support, social and leisure activities, and the severity of the illness.

As such, Westphal-Guitti et al. [22] reported decreased QOL by using the Short-Form 36 health survey questionnaire (SF-36). Women in particular had low scores in the dimensions emotional role, mental health and vitality and in addition reported greater burden using the Burden Inventory (BI). Furthermore, van Andel et al. [12] reported that passive

coping style explained 50% of health-related quality of life (HRQOL) scores of caregivers. They also found that the same domains of caregiver HRQOL were similar to those of the patients with epilepsy, suggesting that the caregivers' well-being may have a spillover effect on the patients' well-being. In contrast, Ohaeri et al. [13] found high QOL scores in caregivers. This result could be explained by the caregivers' ability to respond positively to the challenges of caregiving as a kind of benefit finding. Given that this study was conducted in Sudan, where religious views are strong, another explanation could be that the study participants attributed life events to a higher meaning in their attempt to cope with the challenges of being caregivers of persons with epilepsy.

Because of the high unpredictability and suddenness of seizures, there is reason to believe that anxiety is high among close relatives. In support of this, Thompson and Upton [23] and Lee et al. [24] found the highest levels of anxiety among the primary caregivers (defined as taking on the major task of supporting the patient with epilepsy) in contrast to the secondary caregivers. Also, depression was reported in caregivers in the two studies but with lower scores than anxiety. Of note, Thompson and Upton [23] and Lee et al. [24] are the only two studies that have examined anxiety and depression alone, and therefore more research is needed to confirm their findings.

In addition, Lee et al. [24] found a correlation between perceived lack of seizure control and anxiety and depression. Also, epilepsy variables, such as age at onset of epilepsy, seizure severity, caregivers' concern, and their perceived lack of seizure control, were negatively correlated with the psychosocial adjustment of the caregivers. Thus, the results confirm the assumption that achieving better control of seizures is the key to improving the QOL both in patients with epilepsy and their caregivers.

Furthermore, social support is just as important in caregivers of patients with epilepsy as it is in other caregiver populations. Social support is considered a potential buffer against distress and a predictor of psychological well-being in general [25,26]. However, Thompson and Upton [23] found the level of social support limited in the majority of the primary caregivers, with most support, both practical and emotional, being derived from the family. Even less support was reported regarding external services, which accounted for only 14%. In addition, low perception of practical support influenced the level of depression, and low perception of emotional support from the partner, when caring for an adult family member with epilepsy, also increased the level of depression.

On the contrary, Lee et al. [24] found that half of the primary caregivers reported their level of social support as adequate, with most support being derived from the family both practically and emotionally. Similar results were found regarding the levels of support from external services and the level of emotional support received from agencies outside the family. Also, there seemed to be a strong willingness from the caregivers to receive support from a variety of sources, especially the family members.

Nuhu et al. [27] found caregiver burden associated with unemployment of the person with epilepsy, long duration of epilepsy, and short seizure-free period. In addition, Thompson and Upton [23] reported challenges in primary caregivers' social activities and intimate relationships followed by finance. In sum, caregivers of patients with epilepsy, and especially primary caregivers often being the partners, are affected both psychologically and socially, and as such, epilepsy becomes an identity and the focus of the lives of close relatives. In this regard, social support seems crucial to the well-being of both patients and primary caregivers.

## 4. PTSD in other caregiver populations

Since epilepsy is able to elevate levels of anxiety and other psychological strains in partners given its unpredictable character, it is plausible to hypothesize that partners are at risk of developing PTSD.

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