Master Thesis

Article 1:

A Review of the Psychological Consequences of being a Close Relative of People with Epilepsy – a Sudden, Unexpected, and Potentially Life Threatening Physical Illness

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Résumé

The present master thesis uncovers some of the psychological consequences of being a close relative of a person with epilepsy. This is done in part by reviewing quantitative research conducted until today, and also through an empirical study examining PTSD in partners of epilepsy patients. Consequently, the master thesis expands the research in PTSD to also include partners of people with epilepsy. However, being the first study of its kind, several recommendations for future research are proposed. For example, future research needs to examine PTSD in depth in both patients and partners regarding epilepsy but also in illnesses similar with epilepsy. In relation to clinical practice, the results call attention for therapists focusing on coping strategies, stress intervention, and the importance of social support.

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Article 1

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Abstract

The overall aim of this review is twofold. The first part presents some of the psychological consequences of being close relatives of people with epilepsy. The literature reveals among others that this is associated with caregiver burden, reduced quality of life, anxiety and depression, lack of social support including social consequences such as less time alone to cultivate one's own interests, problems with intimate relationship, and financial difficulties. However, no study to date has looked at PTSD in epilepsy caregivers, which has been found in caregivers to illnesses with similar characteristics as epilepsy.

As a result of these findings, a discussion of whether it is reasonable to hypothesize about PTSD prevalence among epilepsy caregivers is presented. It is concluded that there may be a potential risk of developing PTSD among the relatives of epilepsy patients given the characteristics of the illness and the diagnostic criteria for PTSD, but research is needed to support such a hypothesis. Hence, the second part of the review reports both the research in PTSD concerning the epilepsy population as well as other illness populations similar with epilepsy. Consequently, this is leading to recommendations for future research but also for clinical practice yielding for coping strategies, stress intervention, and the importance of social support as a buffer against developing psychological distress.

Keywords: epilepsy, caregiver, quality of life, PTSD

Psychological Consequences of being a Close Relative

Research into the psychological consequences of diverse illnesses has primarily focused on the patient's point of view. However, there is reason to believe that the close relatives are affected also and often to a larger degree than earlier assumed (Couper et al., 2006; Mosher & Danoff-Burg, 2004; Tuinmann et al., 2004). Consequently, it is also important to tend to the caregivers in order for them to maintain psychological well-being, because they become a resource to the patients. In line with this, research has shown that patients do better both mentally and physically with support, and especially with support from spouses (Nissen, Madsen, & Zwisler, 2008). Fortunately, increasing attention is being paid to the care taking impact on the close relatives.

Below, caregiver burden will be presented. This is followed by some of the empirical findings that focus on the impact on the significant others in order to strengthen the importance of paying attention to the caregivers, when their loved ones suffer from illness.

The term "caregiver burden" is often referred to when focusing on the impact of a chronic illness on family members, and especially regarding those who are most responsible for the caregiving. Chronic illness may involve high caregiving demands and long-term dependencies that cause strains for family caregivers. The burden on the family associated with the patient's illness include both psychologically, physiologically, socially and financially stressors and as such, the concept of burden is viewed as a multidimensional construct. The potential difficulties may consist of direct care needs generated by the illness, financial concerns relating to medical costs and income loss, disruption of normal household routines and roles, and emotional stressors triggered by the illness (Sales, 2003).

The literature distinguishes between two central dimensions of burden, the objective burden that in general is characterized by the direct care tasks stemming from the illness, and the subjective burden defined as the distress experienced by the caregiver in dealing with the objective stressors. However, researchers have difficulties in agreeing about the objective definition of burden, and how best to classify the various components. Inspired by Schene, Tessler, and Gamache's (1994) examination of 21 measures of family caregiving burden and Braithwaite's (1992) discussion, Sales (2003) characterize objective burden as the time and effort required of one person to attend to the needs of the other. The needs may involve helping, supervising, controlling, paying etc. In addition, time and effort is also understood in terms of changed family relation, and social impact in general such as reduced work time and leisure activities. Nevertheless, the measures of objective burden rely on self-reports of the family member. Different researchers have tried to overcome this problem by developing more objective categories. The most comprehensive list is presented by Lefley (1996), who mentions 10 objective burdens for families: (1) patient economic dependence, (2) disruption of daily routines, (3) behavioral management, (4) times and energy demands required to negotiate the mental health system, (5) confusion or humiliating interactions with service providers, (6) financial costs of illness, (7) deprivation of needs of other family members, (8) curtailment of social activities, (9) impaired relations with outside world, and (10) inability to find satisfactory care settings. Even though some of the categories are similar, it is possible to identify some overall dimensions that appear to crosscut measures. These are the direct tasks of care, the indirect tasks of care, dealing with emotional needs of patients, and the effects of caregiving on other life roles.

Subjective burden relates to the caregiver's experience from a more psychological point of view. Thus, this constitutes the emotional component as experienced by the caregiver in dealing with the objective stressors of caregiving. In more specific terms, this emotional component consists of indicators of worrying, distress, stigma, shame, and guilt, and these may contribute to depression and anxiety, which is frequently reported as a consequence of caregiver burden. As such, it is no wonder that close relatives often experience it as a burden in navigating in the caregiver role, which sometimes is pictured as an 'emotional roller coaster'. This picture is also represented in the measurements of caregiver burden with more items dealing with subjective rather than objective strains (Sales, 2003), however, it is important mentioning that subjective burden limited to only affective reactions and emotional well-being is a narrow definition.

In addition, regarding categorization of caregiver burden, the main focus is population specific with difficulties determining the more general aspects across illness groups (Sales, 2003). Still, Biegel, Sales, and Schulz (1991) try synthesizing the common variables affecting burden across illness categories suggesting that the level and types of demands, and trajectory of an illness seems to affect caregiver distress. For example, the patient's cognitive and affective impairment of the illness and thereby change in behavior, regardless of etiology, seems to be more difficult for family members than the physical impairments. Also, illnesses followed by uncertainty, such as patients with stroke or heart failure could elevate anxiety in close relatives (ibid.).

In sum, caregiver burden is characterized by role overload in the term of the objective or subjective burden or both. In line with this, a final point is worth taking into account, namely the impact of caregivers' coping and social support resources on their ability to deal with caregiving demands. This last point will be examined further later in the review.

From an empirically point of view, caregiver burden is extensively examined in light of the chronic illnesses, schizophrenia, and Alzheimer's disease (Sales, 2003). Caregiving for close relatives with dementia appears to be the most burdensome reporting more psychosocial and physical burden than their peers. Specifically, they suffer more often from depression, feel more isolated, perceive their workload as heavier and as such experience pressure on socio-economic life, takes more medication, and are in less good health than caregivers of patients with other illnesses. A prevalence rate of depression in dementia caregivers ranged from 30% to 80%, depending on the study population and the recruiting method. Among the factors that contributed to higher risk of depression were if the caregivers were spouses (in contrast to other next of kin), a higher care need in patients with dementia and strong Activities of Daily Life (ADL)-dependence in a patient, and the behavioral disturbances, that may follow patients suffering from severe dementia. Of these disturbances, especially the uncontrollable and unpredictable character might be responsible for the increased stressful effect. In addition, older caregivers experienced a higher level of depression due to their own physical state and a fear of who was going to take care of their loved one with dementia if they were to die first. On the other hand, younger caregivers developed depression because of a combination of their social position (family, friends, job) and caring for a relative with dementia. Finally, caregivers who perceived their burden heavily along with perceived lack of support and understanding resulted in depressive and stressed feelings. The inverted picture was present when caregivers felt involved and supported in the care situation, and could cope with problems in a way that had a positive outcome on the negative impact of the care situation. Strikingly, however, few data are available on the adaptive coping strategies of caregivers (Shoenmakers, Buntinx, & Delepeleire, 2010).

In regard to patients suffering from heart failure, some of the main findings were caregivers' feelings of being over burdened, stressed and depressed. Specifically, the number of caregiving tasks and the perceived difficulty in performing caregiving activities were variables that increased the level of stress and burden in spousal caregivers. Symptoms of depression were significantly higher in spouses with more caregiving tasks (> 4), and restricted opportunities to engage in activities the caregivers enjoyed increased the depressive symptoms significantly. In spite of these results, the caregivers indicated a willingness to continue providing care for their loved one (Saunders, 2003).

Another frequently referred to illness that causes caregiver burden is multiple sclerosis (MS). Here, it is in particular the unpredictability aspect of the illness in regards to predicting the onset of a relapse, the progression of the disease, or the functional ability of the patient over the course of a day (McKeown et al., 2004). Furthermore, limited participation in usual activities or interests from the caregivers' point of view increased emotional distress among the caregivers (Buhse, 2008). The sense of loss caused by the constant change in disease progression and associated cognitive dysfunction in the patient made the spouses feel that they had lost their partner and their sense of self, companionship, support, income, and lifestyle (Cheung & Hocking, 2004).

In general, mounting evidence suggests that spouses who are faced with the stress of their partners' chronic illness (e.g. dialysis, myocardinal infarction, stroke, head injury) experience declines in both mental and physical health (Keitel, Cramer, & Zevon, 1990). Anxiety and depression were the central features of the distress for both patients and spouses, although spouses exhibited elevations on a wide range of psychological symptoms (ibid.).

Conclusively, the above findings clearly indicates that the detrimental psychological impact on close relatives functioning as caregivers is equally important as the research into this topic seen from the patients' point of view. In addition, the empirical findings showed that some of the consequences of being a close relative resulted in an overall caregiver burden, poor quality of life (QOL), emotional distress, anxiety and depression, although some of the variables may contribute to each other.

Epilepsy

The variables presented above might also be relevant in caregivers of people with epilepsy. Particularly because the characteristics of the illness such as the suddenness of the seizures, give the disease its highly unpredictable character. As such, epilepsy is known to have significant impact on the QOL of patients (Jacoby, Snape, & Baker, 2009), but also on the people surrounding persons with epilepsy (Thompson & Upton, 1992).

Hermann and Whitman (1986) hypothesized three groups of variables that contribute to understanding the impact of epilepsy: 1) neuroepilepsy variables such as age of onset, seizure control, duration, seizure types etc., 2) medication variables including medication type and number and 3) psychosocial variables such as fear of seizure, locus of control, degree of adjustment to the diagnosis, social support, life event changes etc. Unraveling the relative contributions of these three groups has been difficult. However, synergistically they present a fine framework in understanding the impact of epilepsy.

The emphasis usually lies on patients, with less attention to the caregivers, although Svoboda (1979) rightly pointed out that epilepsy is not only an individual but also indeed a family problem. This is in light of the fact that epilepsy is one of the most common neurological conditions affecting about six per 1000 people in European countries (Forsgren et al., 2005).

Consequently, it is the aim of this review to shed light upon the experience of being a close relative of a person with epilepsy and its consequences. To my knowledge there are presently no reviews of this kind. Further, in light of the results of the consequences, the limitations will be uncovered in an assumption to identify the missing pieces in the overall puzzle of being a close relative of a loved one with epilepsy. Finally, recommendations for future research and practice will be presented.

Method

PsycInfo and PubMed were searched to identify relevant material. Search terms used were epilepsy, partner, spouse, family, caregiver, caregiver burden, emotional distress, quality of life, and social support. Exclusion criteria were if research focused on childhood epilepsy, firstly, because much research already exists in this area and secondly because adults is the focus of the present review. Furthermore, patients with additional illnesses or learning disabilities were also excluded to be sure that the experience of being close relatives of persons with epilepsy actually resulted from just that. A second step was to hand search references cited in pertinent articles. The review was confined to articles using quantitative methods and published in English.

Results

Quality of Life

Overall, the literature reveals that epilepsy has a great impact on the lives both to the one that suffers from the illness and the significant others (Table 1). The psychosocial problems experienced by being a close relative typically results in decreased QOL.

Using the Hong Kong Chinese version World Health Organization Quality of Life Measure, Abbreviated Version, Lee et al. (2002) found that three-quarters of the caregivers had below-average domain scores, ranging from 73% of the sample for the Social Relationship domain to 87.5% for the Physical Health domain. A more detailed description was given by Westphal-Guitti et al. (2007) by using the short form 36 health survey questionnaire (SF-36) to measure health status on 8 dimensions: physical functioning, physical role, emotional role, social functioning, mental health, bodily pain, vitality, and general health, and the Burden Inventory (BI) to assess the burden to caregivers. According to the literature, women were most vulnerable when serving as caregivers (Ditlevsen & Elklit, 2010). In this study, they had lower scores in emotional role, mental health, and vitality and reported greater burden. In addition, when the caregivers was responsible for medication or worried about the patient 24 hours a day, they experienced a decrease in QOL; emotional role, vitality, mental health, higher burden for medication, general health, physical functioning, emotional role, mental health, and burden for worrying.

Van Andel et al. (2011) measured QOL in relation to coping style and found that passive coping style explained 50% of the variation in health-related quality of life (HRQOL) scores of caregivers. Also, several domains such as physical functioning, social functioning, mental health, bodily pain, general health, physical component score (PCS), and mental component score (MCS) of caregiver HRQOL were significantly associated to the same domains reported by their partners. This suggests that patient HRQOL may be improved by improving caregiver HRQOL. Similar results are found by Burneo (2009).

In contrast, Ohaeri, Awadalla, and Farah (2009) found a high QOL in caregivers. An explanation could be that caregivers' higher QOL is possibly related to their positive psychological response to the challenge of caregiving as a kind of benefit finding, which has been linked to life satisfaction and coping among caregivers of patients with multiple sclerosis and cancer (Pakenham & Cox, 2008; Kim, Schulz & Carver, 2007). Another explanation is that the study is carried out in Sudan, which is characterized as a religious culture and therefore it is possible that people attribute life events to a higher meaning to better cope with it.

Anxiety and depression

Because of the characteristics of epilepsy, there is reason to believe that anxiety and depression is often reported in significant others. However, only two articles have studied anxiety and depression in family members/caregivers, both using the Hospital Anxiety and Depression Scale (HADS). Out of 44 families with adults epilepsy patients and with the mother as considered to function as the primary caregiver in 35 of the families, Thompson and Upton (1992) found that 16 of the primary carers were considered to have severe levels of anxiety contrary to 3 of the secondary carers, and 4 of the patients themselves. Similar results were found for depression, although less pronounced. When examining the factors that contributed to the high levels of anxiety, these were associated with severity of tonic and atonic seizures, and frequency of episodes of status epilepticus. The last-mentioned was also associated with elevated levels of depression. Comparable results were presented by Lee et al. (2002) with 22% of the caregivers considered to have severe levels of anxiety, and 14% severe levels of depression.

Finally, Lane et al. (1998) studied the correlation between depression and burden, which resulted in a strong positive relationship with 15% of the caregivers classified as being at least mildly depressed. However, this population was not endorsing symptoms of depression with the mean Beck Depression Inventory (BDI) score at 5.7 (*SD* = 5.5), with a range of 0-23. As such, those who were depressed also reported burden, although many caregivers reported burden without an emotional component. Therefore, it is important to view burden as a multidimensional construct and use an instrument that taps multiple dimensions. This is in accordance with Sales' (2003) note presented earlier. Also, coping skills were associated with depression with wishful thinking coping skills explaining 70% of the variance in caregiver depression. The result is consistent with the literature, where studies of other conditions show that emotion focused coping strategies such as denial and wishful thinking are typically associated with poor adaptation, whereas problem focused strategies tend to be associated with better adjustment (Moss-Morris, Petrie, & Weinman, 1996). All in all, this suggests that intervention aimed at enhancing coping strategies may reduce depression and relieve burden.

Social support

Generally, social support is considered a potential mediator or buffer against distress and a predictor of psychological well-being among individuals who experience traumatizing events (Elklit, Pedersen, & Jind, 2001; Cohen & Wills, 1985). As Joseph (1999) notes, it helps explain why some individuals develop severe or chronic psychological distress while others do not. This is in line with Buunk and Hoorens' (1992) assumption that social support from significant others is of major importance in coping with important life events.

The level of received support is reported to be limited by the majority of the primary caregivers in Thompson and Upton's (1992) study, with most support, both practical and emotional, being derived from the family. Only 14% believed they had considerable support from external services and 2% considerable emotional support from agencies external to the family. In addition, they found that the lower the practical support perceived, the higher levels of depression, and finally, the lower the perceived emotional support from a partner, when caring for an adult family member with epilepsy, the higher the level of depression.

In line with this, Sarason, Sarason and Pierce (1990) distinguish between perceived support, that is the perception that support will be available if it were required, and received support, which is the support actually received. This suggests that the influence of received support is in fact mediated by perceived support (Wethington & Kessler, 1986), and that the mere perception that support is available can reduce stress (Buunk & Hoorens, 1992).

More precisely, Elklit, Pedersen, and Jind (2001) suggest, *"since perception will always play a role in terms of what is received, a more precise distinction might be between (perceived) availability and (perceived) received support"* (ibid. p. 1292). Furthermore, Sarason, Sarason, and Pierce (1990) end up concluding that social support is best defined as a multifactoral and heterogeneous construct.

A more positive picture is presented by Lee et al. (2002), where half of the primary caregivers rated their level of social support as adequate, with most support, both practical and emotional, being derived from the family. Also, the levels of support from external services and the receiving of emotional support from agencies external to the family were rated higher. Willingness to accept help was rated high with the majority of the caregivers revealing that they were willing to receive support from a variety of sources, especially from family members.

One explanation of the contradictory findings from the two studies could be that Lee et al.'s (2002) research is conducted in Hong Kong that is considered a collectivistic culture, which is characterized by higher levels of support and from the family particularly. It is not due to heterogeneity in measurements, which is a common explanation regarding diverging results, because the scale Lee et al. (2002) used to assess the level of leisure activities and perceived support of caregivers was based on the report of Thompson and Upton (1992).

Impact after Surgery

Witnessing a loved one having a seizure often contribute to caregiver distress. Even though patients are obtaining surgical treatment for epilepsy, this is not necessarily synonymous with a decrease in the levels of burden. In keeping with this, using the Blessed Dementia Rating Scale, Lane et al. (1998) found a negative relationship between functional performance of the patient and increased burden, which mean that poorer functioning or negative change in the patient may contribute to caregiver burden. Specifically, the results showed a strong correlation between two of the three dimensions of the Blessed Dementia Rating Scale, namely personality change and cognition – and not activities of daily living – in epilepsy patients following surgical treatment and the Caregiver Strain Index (CSI). Seizure control, measured by the number of seizures experienced by the patient after surgery, was not significantly correlated to burden. Still, seizure control plays a role in burden to a certain degree, because a small number of patients continued to have seizures, which affected the caregivers who endorsed higher levels of burden. The same pattern was seen with caregivers of seizure-free patients, which is explained by the follow-up studies that revealed no changes postsurgery in burden or patient functioning, suggesting a more chronic pattern of dysfunction in the caregiver and the patient.

Following this, Langfitt et al. (1999) examined family interactions associated with psychosocial outcome of epilepsy surgery and found that positive family affective climate and family support of patients' autonomy were associated with better social adjustment among patients after surgery. A reasonable explanation is that patient's social adjustment and family effective climate co-evolve and mutually influence one another. Given the findings mentioned above, it could be hypothesized that family interactions and this mutual relationship between family affective climate and the family support of patients' autonomy might reduce the chronic pattern of dysfunction between the patient and the caregiver as presented by Lane et al. (1998).

The Lived Experience of Epileptic Seizures by the Caregivers

A different perspective on being close relatives of people with epilepsy is presented by Pinikahana and Dono (2009) who studied the lived experience of initial symptoms of and factors triggering epileptic seizures both in those who suffer from the condition and their caregivers. Due to the focus of the present review, only the caregiver's results from this study will be presented. The majority of the caregivers (74%) were aware of initial symptoms of epileptic seizures. The most common symptoms were funny feeling, confusion, and anxiety. Those caregivers that experienced one trigger resulting in a seizure accounted for 85.5%. The most frequently reported triggers were stress, tiredness, and sleep deprivation. Half of the responding caregivers were able to tell when a seizure was about to occur, and 15.4% felt they could stop a seizure by using resting and relaxation techniques as well as medication.

Generally, not much research exists in this area, and what have been studied previously reported a lower percentage in the experienced initial symptoms prior to seizures. However, the study points to the conclusion that close relatives are aware of preseizure activity and to a certain degree are capable of identifying the circumstances that causes seizures. Furthermore, it is suggested that significant others have good insight into preseizure activity, since the caregivers' responses were very similar to the ones with epilepsy (ibid.).

Expressed Emotion in Relatives and Nonepileptic Seizures

The term 'expressed emotion' (EE) refers to a standardized method of rating types of remark and tone of voice used by one person when referring to another during the Camberwell Family Interview. The components of EE are critical comments, hostility, emotional overinvolvement (EOI), warmth and positive remarks (Brown & Jadresic, 2000; Bledin et al. 1990).

Brown and Jadresic (2000) examined EE in families and found that the degree of seizure control in the adult person with epilepsy (age span between 15 and 25) is related to parental EE. More specific, mothers tended to exhibit high EE by EOI, and fathers by making critical comments.

Stanhope, Goldstein, and Kuipers (2003) studied the relationship between EE, depression, and coping both in relatives of people with epileptic and nonepileptic seizures. A nonepileptic seizure (NES) is characterized by a sudden change in the person's behavior, thinking, perception or feeling that resemble, or is mistaken for, an epileptic seizure, but it is not accompanied by the abnormal paroxysmal EEG discharges that occur in real epilepsy (ibid.). The epilepsy relatives that were classified as high EE accounted for 53% and 47% were low in EE. None of them differed in mean anxiety or depression score, although 42% with high- and 18% with low-EE had "clinically significant" anxiety score with a cut-off at ≥ 11. Finally, both high- and low-EE epilepsy relatives used problem-focused coping strategies more than half the time. In NES relatives, 71% demonstrated high EE contrary to relatives low in EE, which accounted for 29%. EOI alone or with critical comments and hostility was reported by 53% of the NES relatives and only 37% of the epilepsy relatives, whereas the result was inverted when it came to expressed hostility with 20% of the NES relatives and 37% of the epilepsy relatives. None of the other results met the level of significance. As such, high-EE NES relatives may attribute difficult behaviors more to the patient than to the illness, and adjustment difficulties therefore may arise because of insufficient understanding by the relatives in order to know which changes are and are not related to epilepsy symptoms. Furthermore, in NES families, anxiety could reflect a more dysfunctional family environment, which results in the tendency to communicate distress in maladaptive ways such as avoiding communication. This calls for attention that educating the relatives, and not only the patients, might be beneficial.

In line with the Stanhope et al. (2003) findings, Wood et al. (1998) uncovered more health problems, distress, and criticism in NES families than in epilepsy families. In contrast to this result, the patients with NES and epilepsy did not differ in any of the measures. This suggests that being a witness in the light of a close relative of people with a chronic illness is sometimes more difficult than being the one, who suffers from the illness as supported by Couper et al. (2006), Mosher and Danoff-Burg (2004), and Tuinmann et al. (2004) too. Of note, it is worth considering that Wood et al. (1998) end up concluding that the families of patients with epilepsy are relatively healthy. This might be the overall conclusion in their study, but all the above findings in this review present a quite different picture, suggesting that the article of Wood et al. (ibid.) would be strengthened by comparing their results to other research in the area concerning epilepsy and not only research in NES families.

Social Consequences

So far the psychological consequences have been uncovered and thereby primarily the subjective dimensions of burden with reference to Sales' (2003) distinctions. However, research has also been conducted into the objective dimensions of burden. As such, the social aspect of being a significant other is also relevant. This includes different kinds of tasks such as driving and more working hours, since the loved one with epilepsy is prevented doing it because of the risks of seizures. In addition, higher well-being in epilepsy patients seems to be significantly associated among other things with having experience epilepsy for a long time, infrequent seizures, and being employed full-time (Collings, 1990).

This is supported by Thompson and Upton (1992), where the primary caregivers (defined as taking on the major task of supporting the epilepsy patient) reported most problems in the area of social activities and intimate relationships followed by finance. Furthermore, the primary caregivers' social and leisure activities were markedly reduced with 26 out of 44 persons reporting having less than once a month off to take care of social interests. Those who had not spent a night away from the person with epilepsy in the previous year, accounted for 31 caregivers, and 32 had not had a holiday with the loved one with epilepsy in the last 5 years. Also, Nuhu et al. (2010) examined caregiver burden, which were reported high by 51.9% of the caregivers. Among the significant variables associated to burden were the patient's unemployment, long duration of epilepsy, and short seizure-free period.

Discussion

This review has presented some interesting results (Table 1). Some of the main findings will be discussed below closing with a section of what remains understudied concerning the consequences of close relatives of epilepsy patients.

The overall experience of being close relatives of people with epilepsy consists of decreased QOL and a risk of developing anxiety and depression depending on the frequency and severity of seizures. An underlying assumption here is that the unpredictability of the seizures elevate especially anxiety, but also stress arousal. Caregiver burden, in general, also influence on the psychological well-being of the caregivers, and it is specifically women who reported greater burden. This is in accordance with the literature, which shows that women are twice as vulnerable as men (Ditlevsen & Elklit, 2010; Spindler et al., 2009). In addition, worrying and being responsible for medication were some of the variables that contributed to burden.

Another interesting finding is that negative change or poorer functioning of the patient contributed to caregiver burden as well, with the results stemming for the Blessed Dementia Rating Scale on the dimensions personality change and cognition. A parallel is worth making regarding to the findings from the research in dementia where is also was the uncontrollable and unpredictable character of the illness that was considered a strong risk factor for depression among caregivers (Shoenmakers, Buntinx, & Delepeleire, 2010). Anxiety was not measured in the review by Shoenmakers et al. (ibid.), but it is reasonable to hypothesize that anxiety or symptoms of it would be present in populations of dementia caregivers too given the findings from the epilepsy caregivers presented here.

Furthermore, coping style was of significant relevance in the well-being of the relatives with wishful thinking as a coping style increasing the level of depression, whereas problem focused coping style was associated with better adjustment. Regarding better adjustment, social support was essential in the caregivers' well-being with actual received support having a positive influence on the psychological well-being. In contrast, the need for social support increased the risk of psychological distress. As such, the caregivers carried the burden themselves with a limited number of persons that were actually able to help the relatives whether it was the objective or subjective burden that mattered. Of note, there were only two articles to be found when searching for social support concerning close relatives of epilepsy patients. Further research needs to be conducted in order to gain in depth knowledge on this area, especially in light of the fact that the phenomenon is studied in many other illnesses with results revealing the importance of social support to maintain psychological well-being.

Furthermore, social support showed more negative results from a Western (Thompson & Upton, 1992) than from an Eastern (Lee et al., 2002) point of view. A similar picture resulted from the findings of Ohaeri, Awadaila, and Farah (2009) that reported high QOL in the caregivers in Sudan, whereas Whestphal-Guitti (2007) from a more Western point of view reported low QOL in the caregivers. The results suggest that collectivistic cultures play a role in decreasing psychological distress in caregivers, whereas individualistic cultures seem to play a potential role in increasing psychological strain. Also, religion plays a major role in collectivistic cultures indicating that caregivers tend to attribute life events to a higher meaning to better cope with the experienced burden. Benefit findings in the challenges of being close relatives is as such linked to life satisfaction and coping. All in all, this yields to a different understanding of the term “caregiver burden” than what has been the determining focus so far, i.e. ignoring the positive aspect of caregiving that emphasize the satisfactions related with giving care. Most family members do not consider giving care as a burden. Rather, it is a natural outcome when someone in ones family is diagnosed with a chronic illness because they love each other; it is part of the expected role, and often to reciprocate for their past care for the healthy part too. Thus, the term “burden” ignores the affective, contextual, historical, and relational elements of the role that may be most central to the caregivers with narrowing the understanding to only encapsulate the negative equation by which its impact primarily is being viewed. Hence, acknowledgement of the satisfaction and rewards of caregiving deserves more attention than given so far (Sales, 2003).

Finally, caregivers of people with epilepsy were aware of initial symptoms of epileptic seizures and half of them were able to tell when a seizure was about to occur. An interesting hypothesis drawn from these results and in the light of research conducted from especially anxiety, could be that caregivers who are aware of preseizure activity and were capable of identifying the circumstances that causes seizures might experience less anxiety than caregivers who experience seizures as unpredictable and uncontrollable. However, to date, no studies have examined this relationship.

The seizure frequency also had social consequences in the relatives resulting in more caregiver burden when patients were unemployed; the duration of epilepsy was long and with only short seizure-free period. Further, it resulted in less leisure activity, challenges in intimate relationships, and worrying over finance with a reduced income, when only one was working.

So far, the review has tried to uncover all significant aspects of the lived experience of being close relatives of people with epilepsy stemming from the research conducted until now (Table 1). The primary focus has been caregiver burden and its multidimensional constructs, such as addressing tension and anxiety changes in dyadic relationships and time infringements resulting from caregiving. Thus, the results encapsulate both the objective and subjective dimension of burden presented earlier by Sales (2003). The results are supported by Savundranayagam, Montgomery and Kosloski (2011), who studied caregiver burden among spouses and adult children of persons with chronic illnesses in general.

Table 1: Studies reviewed

Article	Year	Sample size	Focus
van Andel et al.	2011	105 patients 86 couples	Focus on health related quality of life (HRQOL) and coping style on both patients and caregivers and their interaction.
Nuhu et al.	2010	231 caregivers	Assess the level and correlates of burden among caregivers.
Burneo	2009	37 patients 37 caregivers	A study of whether quality of life (QOL) of caregivers of adults with intractable epilepsy was reduced and which factors accounted for this.
Pinikahana & Dono	2009	225 PWE* 78 caregivers	To examine the self-perception of initial symptoms and triggers of epileptic seizures; to investigate the perceived self-control in managing epileptic seizures and the techniques used; and to explore differences in demographic characteristics, living with epilepsy characteristics, and seizure types in relation to seizure prediction and self-control for PWE and the caregivers' perception of it as well.
Ohaeri, Abdel & Farah	2009	275 patients 257 caregivers	To asses the subjective QoL of epilepsy patients and their family caregivers, compared with the general population, and previous data for chronic conditions in Sudan, and to examine the predictors of QoL.
Westphal-Guitti et al.	2007	100 patients 100 caregivers	To evaluate and compare QoL and burden in caregivers with patients suffering from temporal lobe epilepsy and juvenile myoclonic epilepsy, respectively.
Stanhope, Goldstein & Kuipers	2003	57 key relatives	Study Expressed Emotion (EE) in relatives of people with epileptic and nonepileptic seizures (NES).
Lee et al.	2002	65 caregivers	To explore the factors associated with the quality of life and emotional states of the caregivers.

Brown & Jadresic	2000	Parents of 41 PWE	To investigate the relationship between parental EE and seizure control in young people with epilepsy.
Ellis, Upton & Thompson	2000	Review	Review
Langfitt et al.	1999	43 patients 89 family members	To identify family interactions associated with psychosocial outcome of epilepsy surgery.
Wood et al.	1998	18 patients and their family members	Compares families of patients with psychogenic seizures (PS) and patients with epilepsy
Lane et al.	1998	34 caregiver-patient dyads	To determine the incidence of perceived caregiver burden in caregivers of patients following surgical treatment for epilepsy. Factors included in the study was caregiver depression, caregiver coping skills, the caregiver's evaluation of the patient's functioning, demographic information, and the patient's seizure control.
Thompson & Upton	1992	44 families	To explore the psychological and physical well-being, satisfaction with social circumstances and perceived level of support in families with an adult member of epilepsy.

* PWE = People With Epilepsy

While reviewing the literature concerning the psychological consequences of being a close relative of persons with other chronic illnesses, a couple of other perspectives were raised. For instance, sleep disturbances has been found in spousal caregivers of individuals with dementia. Various nocturnal behaviors by the loved one with dementia were reported by the caregiver such as restlessness, wandering, and requests for help. Furthermore, using the SF-12, the results showed that a high frequency of nocturnal disruptions was correlated with poorer caregiver mental health (Cresse et al., 2008). Sleep disturbances in spousal caregivers of epilepsy patients may also play a role during preseizure activity. As such, restlessness, but also abnormal breathing, may be present in epilepsy patients during the night influencing the caregivers' sleep. This is supported by Pinikahana and Dono (2009), although they did not study the correlation between sleep disturbance and mental health.

In addition, PTSD has never been studied in the area of epilepsy, although PTSD has been found in other caregiver population such as cancer. For instance, Kazak et al. (1997) found PTSD in cancer patients and their caregivers. Additionally, some studies have examined the psychosocial impact and distress in relatives of cancer survivors and found that relatives are often as distressed or even more distressed than the cancer survivor themselves (Couper et al., 2006; Mosher & Danoff-Burg, 2004; Tuinmann et al., 2004). Elklit et al. (2010) examined PTSD among bereaved relatives of cancer patients and found a PTSD prevalence of 40%. The relatives were aged 14 to 76 years, and time since the loss was a minimum of one month. A long period of caretaking, high levels of somatization, and dissociation was identified as risk factors elevating levels of PTSD, whereas full-time employment, perceived control, and a secure attachment style were variables associated with decreasing levels of PTSD.

Conclusively, with reference to the three groups of variables that contribute to understanding the impact of epilepsy presented by Hermann and Whitman (1986) earlier, many of the variables have been reviewed. Of note, the variables are primarily concerned with the impact from the epilepsy patient's point of view, although this review has shown that the variables influence the caregivers as well. The neuroepilepsy variables that were studied were seizure control, duration and seizure types, but age of onset of the epilepsy was not. Therefore, it would be interesting to examine the correlation between age of onset and caregiver burden. The reason is that Lee et al. (2003) found a negative correlation between epileptic variables including age of onset of epilepsy, seizure severity, caregivers' concern, and their perceived lack of control and psychological adjustment of the caregivers, and thus the caregivers may perceive a greater burden too.

Moreover, medication variables have not been studied in depth in relation to the potential impact on caregivers, however it is reasonable to hypothesize that the medication the epilepsy patient is taking to decrease the seizures may decrease the burden as experienced by caregivers. Finally, psychological and social variables in general have been studied to a certain degree, but research is still needed. Moreover, locus of control and degree of adjustment to the diagnosis yields for further research.

It is beyond the limits of the present article to examine all the perspectives just mentioned. However, in order to strengthen this review's second aim, the next sections will present a discussion of whether it is reasonable to include a PTSD hypothesis concerning epilepsy relatives by reviewing illnesses that parallel with epilepsy and which found PTSD in caregivers, firstly, and thereafter compare these findings to epilepsy caregivers also by referring to the PTSD criteria. In line with this, other relevant illnesses where researchers have found prevalence of PTSD but in patients will be presented in order to uncover paralleling illnesses that may where caregiver PTSD is a risk too. Conclusively, the review ends with recommendations for future research and practice.

PTSD in Partners

The *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) defines PTSD as *"Experiencing, witnessing or confronting events that involve actual or threatened death or serious injury, or a threat to the psychical integrity of self or others"* as a potentially traumatic event (American Psychiatric Association, 1994). This definition was based on the work of Nir (1985) and Pot-Mees (1989) about PTSD in childhood cancer survivors, and the first quantitative pilot report by Stuber et al. (1991), who both found that children followed by bone marrow transplantation were suffering of posttraumatic stress reaction. Furthermore, *"being diagnosed with a life threatening illness"* was added as an example of traumatic stress in DSM-IV (American Psychiatric Association, 1995). Alter et al. (1996) and Pelcovitz et al. (1996) reflected these findings from their studies of PTSD in childhood cancer survivors and their parents, and as such, the area concerning close relatives gave rise to further research.

Nevertheless, not only cancer patients and caregivers are affected. In light of the abovementioned criteria, there is reason to believe that other illnesses also could pose a risk for PTSD development in both patients and relatives e.g. heart transplantation and implantation of a mechanical assist device followed by heart transplantation. Given the life-and-death consequences of heart transplantation and the often long waiting time for a donor heart, it is no surprise that some recipients and their close relatives experience a variety of distressing features associated with psychological trauma. Similar aspects are present with implantation of mechanical assist devices. The same technical environment that serves as a life-saving intervention can, however, also be accompanied with severe emotional stress both in the patients and their close relatives. Such aspects of sudden and unexpected features caused by the illnesses are some of the core elements in the PTSD diagnosis (Kessler et al., 1995)

This is supported by Stukas et al.'s study (1999) that investigated PTSD in heart transplant recipients and their primary family caregivers. They studied 158 recipients and 142 family caregivers, by using a structured, standardized interview and DSM-III-R criteria. They found that among the recipients, 10.5% met full criteria for PTSD and an additional 5% were probable cases. The rate was a bit lower in caregivers with 7.7% meeting the full criteria for the disorder and an additional 11% were probable cases. The risks for PTSD were increased if the participants were females, had a history of psychiatric illness, and had lower friend support.

Additionally, Dew et al. (2004) studied prevalence and risk factors for depressive and anxiety-related disorders in 190 caregivers to heart transplant recipients throughout 3 years. The methods used were the Structured Clinical Interview for DSM-III-R (SCID) and the Composite International Diagnostic Instrument (CIDI) to assess transplant related PTSD (PTSD-T). By the end of the 3 years post-transplant, cumulative onset rates of the cohort were: Major Depressive Disorder (MDD) 31.6%, Adjustment disorders 35.4% (29.4% with anxious mood), PTSD-T 22.5%, Generalized Anxiety Disorder 7.3%, and any assessed disorder 56.3%. The disorders' rates increased over the entire study period, except PTST-T, which occurred primarily during the first year post-transplant. The most commonly cited aspect of the transplant experience that provoked post-transplant reactions was the period of waiting for a donor heart (33%). This was followed by learning about the recipient's need for a transplant (15%), and the initial evaluation for transplant (27%). The risk factors that were identified were strengthened by positive lifetime history of psychiatric disorder, greater post-transplant caregiving responsibilities, and a poorer relationship with the patient. Moreover, risk for MDD was increased by caregiver unemployment, and risk for anxiety disorders was increased by younger age, low sense of personal mastery, and high use of avoidance coping strategies.

Bunzel et al. conducted three studies in the period from 2005 to 2008 studying PTSD in partners and patients who had undergone implantation of a mechanical assist device followed by heart transplantation. The respondents varied from 30 to 41 patients, and 21 to 27 partners. The methods used were the Impact of Event Scale-Revised (IES-R), Hospital Anxiety and Depression Scale (HADS), and Artificial Heart Questionnaire, a questionnaire about specific problems regarding the time on the device. None of the patients in any of the three studies met the criteria for a PTSD diagnosis. However, overall 23%-27% of the partners did. Furthermore, symptoms of depression and anxiety were found in the two studies that used the HADS in both patients and partners, but the majority was reported by the partners, with 2% of the patients who showed mild to moderate depression, and 4% of the patients reported mild to moderate anxiety. In contrast, 19% of the partners showed mild to moderate depression, and 24% reported mild to moderate anxiety.

In sum, the abovementioned studies showed that there is a prevalence of PTSD in caregivers to heart transplant patients and caregivers of patients having an implantation of a mechanical assist device followed by heart transplantation. Furthermore, anxiety and depression were also commonly reported. Among the risk factors identified regarding PTSD were being female, lifetime history of psychiatric disorder, and low friend support. For depression, the main risk factor was caregiver unemployment, whilst younger age, low sense of personal mastery, and high use of avoidance coping strategies were measured as risk factors in developing anxiety.

PTSD in Partners of People with Epilepsy?

The studies presented so far indicate that there is a risk of developing PTSD when living with and thereby witnessing a person who suffers from illnesses that have aspects of suddenness, unpredictalbleness and may be potentially life threatening. Epilepsy is also characterized by unexpected seizures and potentially life threatening events giving rise to worries in the partner for not knowing when an epileptic fit may occur, nor its severity or duration. In light of the PTSD diagnosis in DSM-IV (American Psychiatric Association, 2000), the relatives may be witnessing the seizure or be confronted with the consequences of it when they get home, the fits are potential of causing serious injury and even death. These characteristics make up the A1 criterion. Typically, the situation the relatives are confronted with involve intense fear, helplessness or horror, as seen in the studies of Thompson and Upton (1992) and Lane et al. (1998), and this accounts for the A2 criterion. This is also in line with the hypothesis set forth earlier that if significant others were able to identify and prevent an epileptic fit with some of the techniques known as helpful, such as relaxation and mediation, this could probably decrease the level of anxiety, and the likelihood of developing PTSD.

In addition, the recurring aspect of the seizures and the unpredictability associated with them could be considered as the B-criterion of a PTSD diagnosis, which is identified as repetitions of the trauma including intense psychological stress. The C-criterion could arguably be met by the fact that epilepsy is a chronic disorder, thus potentially resulting in avoidance of stimuli associated with the trauma e.g. a decreased interest or participation in important activities. This could probably both be due to the amount of caregiver burden and a fear of leaving the loved one that suffers from epilepsy alone, thereby disabling themselves from participating in other activities (Lee et al., 2002; Thompson & Upton, 1992). The D-criterion concerns continuous symptoms of elevated arousal e.g. over vigilance, irritability, and burst of anger. This was found expressed in the results from the studies of caregiver burden and QOL (e.g. Lee et al., 2002; van Andel et al., 2011) and in addition from the studies concerning EE with 37% of the epilepsy relatives expressing hostility (Stanhope, Goldstein, and Kuipers, 2003). The final two criteria, E characterized by the duration and F characterized by clinical strain or a reduction in social activities, employment or other important duties, also hold support in the empirical literature. Both criteria were supported in the study of Nuhu et al. (2010), where the patient's long duration of epilepsy and short seizure-free period had a significant influence on caregiver burden. In the study of Thompson and Upton (1992) partners reported problems with finance and social activities.

Besides the stressor criterion A, three symptom-clusters must be present for at least one month (E); re-experiencing of the traumatic event (B), avoidance of trauma related stimuli and numbing of general responsiveness (C), and a heightened physiological arousal (D). Finally, the symptoms must be clinically significant (F). However, relatives will probably also express subclinical symptoms (see Appendix A).

Thus, supported by the results from the literature review of epilepsy caregivers, PTSD in caregivers of other paralleling illnesses, and the PTSD criteria, there seems to be a risk that close relatives of people with epilepsy may develop PTSD, and as such, a new piece of the puzzle of the lived experience of being significant others is identified.

Other Relevant Illnesses with a Prevalence of PTSD

Several illnesses have been argued to elevate risk of PTSD such as heart transplantation, implementation of mechanical assist device, and hypothetically epilepsy too. Additionally, in uncovering the perspective of PTSD, Tedstone and Tarrier (2003) argue that, for example, myocardial infarction (MI), cardiac surgery, hemorrhage, or stroke may be sudden, unexpected and immediately life threatening and as such also be risk factors in developing PTSD. Four studies from their review report a prevalence rate of PTSD in MI patients ranging from 0% to 16%. The variance in the results could be explained by a variety of designs and measures of PTSD. Nonetheless, Spindler and Pedersen (2005) identified eleven studies examining the prevalence of PTSD after MI and found a variation in the prevalence of 0% to 22%. Of note, PTSD has also been most rigorously researched in MI patients. In the review by Tedstone and Tarrier (2003), the study that reported the lowest PTSD rate (0%) was a prospective study by Van Driel and Op den Velde (1995) measuring PTSD by using a diagnostic interview (Structured Clinical Interview for DSM-IV). Symptoms were measured at 22-26 month post-MI, whereas the other three studies measured PTSD much earlier, that is 3 to 14 month post-MI. Kutz et al. (1994) reported the highest rate (16%) and used a weaker retrospective design with questionnaire assessment. Similar results are reported following cardiac surgery with prevalence rates for PTSD ranging from 10.8% to 18%. Also, in a study of subarachnoid (brain) hemorrhage by Berry (1998) with 28 patients, a total of 32% met the DSM-III-R criteria for PTSD. O'Carroll et al. (1999) conducted a study on PTSD and variceal hemorrhage (severe bleeding from the esophagus) with 30 patients. Even though they had bled more than 4 units of blood, and the majority found the experience distressing, only one person reached the DSM-III-R criteria for PTSD. The fact that 29/30 of the bleeds happened at the patient's own home, the authors hypothesized that the patients were forced to habituate to the trauma, because it would be difficult for them to avoid bleeding. Additionally, most of the patients were men who abused alcohol. As Tedstone and Tarrier (2003) argue, the men who abused alcohol could have developed some coping strategies, for example denial, and which could have lowered the prevalence rate.

Finally, PTSD was also found in patients who suffered from stroke. Sembi et al. (1998) studied 61 patients of whom 9.8% fulfilled the criteria for PTSD after experiencing their first stroke or transient ischemic attack (TIA). The measurement was the Clinician Administered PTSD Scale (CAPS). In summary, Tedstone and Tarrier (2003) concludes that areas where there could be a potential prevalence of PTSD are far from uncovered, and further research is needed to identify all relevant illnesses. Also, future studies need to be conducted with more systematic and methodic rigor. More specific, methodological issues influencing the prevalence rate, for example choice of instrument (e.g. self-report versus diagnostic interview), the nature of the illnesses, the power of the study and which parameters to assess (e.g. aspects related to the illness, clinical, social or demographic variables) need to be carefully considered. Of note, Spindler and Pedersen (2005) reviewed the prevalence and risk factors of PTSD in cardiac patients with similar remarks concerning future research directions. Furthermore, Tedstone and Tarrier (2003) discovered that the relatives of the patients were much more traumatized than the patients themselves. This is in line with findings of Couper et al. (2006), Mosher and Danoff-Burg (2004) and Tuinmann et al. (2004) presented earlier. Therefore, it seems reasonable to hypothesize that this phenomenon is present in relatives of people with epilepsy too, yielding for PTSD research both in those that suffer from the illness and the caregivers.

Recommendation for Future Research and Practice

In light of the results presented in this review, a number of recommendations for future research and practice will now be presented. In general, the literature concerning close relatives of people with epilepsy is sparse, yielding for more research on the area. This is surprising, since epilepsy is the most common neurological condition after headache (Forsgren et al., 2005).

One of the main aims of this review was to discuss whether it is reasonable to examine PTSD in relatives of people with epilepsy given the results of PTSD in caregivers, whose loved ones were heart transplant patients or having an implantation of a mechanical assist device. Together with the PTSD criteria, it was assumed that there is indeed a potential risk of developing PTSD when being a close relative of an epilepsy patient, and this should therefore be investigated. Going even further, findings from Couper et al. (2006), Mosher and Danoff-Burg (2004), and Tuinmann et al. (2004) suggested that relatives of people with similar illnesses to epilepsy often are even more affected than the patients themselves, which from a PTSD point of view never have been examined either. Therefore, further research is needed to investigate PTSD in both epilepsy patients and caregivers. This includes more research regarding the relatives' ability to identify and to a certain degree prevent the seizures using diverse techniques, and thereby decreasing the level of experienced anxiety and, in worse cases, PTSD.

For clinical practice, the review also paid attention to the effort needed regarding epilepsy relatives. For example, the result from van Andel et al.'s study (2011) that coping style explained 50% of the variation of HRQOL scores of caregivers give rise to making interventions and educating relatives in different kinds of coping strategies. Specifically, how to use problem focused strategies i.e., identifying problems, determining options, evaluating options and choosing the best one, acting, and seeing if it works. Moreover, benefit finding and attributing life events to a higher meaning, either religious or by trying to find meaning in the role as caregiver, seem to be beneficial in reducing depression and relieve burden (Pakenham & Cox, 2008; Kim, Schulz & Carver, 2007) yielding for more research concerning epilepsy caregivers. As such, relatives need help to help themselves, because they become a resource to the patient (Nissen, Madsen, & Zwisler, 2008).

In spite of this, it is important to bear in mind that the coping strategies one tends to use may depend on personality type. For instance, the distressed (type-D) personality, as characterized by high scores on the two stable personality traits negative affectivity and social inhibition, may cope by using emotion focused strategies such as denial and wishful thinking. Furthermore, the type-D personality is characterized by having a gloomy outlook on life, a tendency to feel sad, an increased experience of negative emotions (i.e. high negative affectivity), and by not sharing these emotions with others because of the fear of how others may react (i.e. social inhibition) (Spindler et al., 2009). Also, emotion focused coping strategies are associated with depression and are found in type-D personalities (Moss-Morris, Petrie & Weinman, 1996). In spite of this, the impact of type-D personality is independent of mood states, such as depression, in that type-D represents a normal personality construct (Spindler et al. 2009). Nevertheless, type-D can potentially become a chronic factor (≥2 years), whereas depression comprises an episodic risk factor (<2 years) and thus is a measure of psychopathology (Pedersen & Denollet, 2006).

In addition, stress point intervention is empirically proven to be helpful (Ogden et al., 1997). Educating relatives about the epilepsy, its consequences and impact both social and psychological, will probably result in enhanced coping outcomes and thereby family function in general, but also the dyadic function between the significant other and the epilepsy patient. By improving caregiver QOL as spill over effect may be seen on the patient QOL as well, as van Andel et al. (2011) suggested in their article.

Finally, social support was considered a buffer against psychological strain. Nevertheless, the results from the review by Thompson and Upton (1992) and Lee et al. (2002) revealed that social support both practically and emotionally primarily were received from the patient's family. This indicates a need for including the network besides the family, e.g. external agencies and support groups for relatives, in this type of research. This way it will be possible to look at the phenomenon from a more system theoretically perspective contrary to merely having an individual focus. A worthwhile note regarding social support, including the other interventions mentioned here, is the importance of individualized strategies of intervention processes in a way that the relatives experience it as helpful instead of as an additional challenge in their role as caregivers to epilepsy patients.

Conclusion

Close relatives seem to be just as affected as other caregiver populations when taking care of epilepsy patients, both regarding the social and psychological aspects of life. Among the findings reported in this review were decreased QOL and a potential of developing anxiety and depression caused by the frequency and severity of seizures. These were also central features together with the criteria for the PTSD diagnosis and the findings of PTSD in caregivers from paralleling illnesses. Thus, it is arguably a potential risk of developing PTSD when being a significant other of a loved one with epilepsy, although further research is needed to support that assumption. Additionally, the findings call for attention to systematically conduct more research in illnesses that may cause PTSD in patients as well as caregivers. Finally, the review led to a conclusion that intervention and education to the relatives of people with epilepsy in coping strategies, stress intervention and the importance of social support is crucial.

APPENDIX A

DSM-IV-TR criteria for PTSD

Criterion A: stressor

The person has been exposed to a traumatic event in which both of the following have been present:

1. The person has experienced, witnessed, or been confronted with an event or events that involve actual or threatened death or serious injury, or a threat to the physical integrity of oneself or others.
2. The person's response involved intense fear, helplessness, or horror.

Criterion B: Intrusive recollection

The traumatic event is persistently re-experienced in at least one of the following ways:

1. Recurrent and intrusive distressing recollections of the event, including images, thoughts, or perceptions.
2. Recurrent distressing dreams of the event.
3. Acting or feeling as if the traumatic event were recurring (includes a sense of reliving the experience, illusions, hallucinations, and dissociative flashbacks episodes, including those that occur upon awakening or when intoxicated).
4. Intense psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event.
5. Physiologic reactivity upon exposure to internal or external cures that symbolize or resemble an aspect or the traumatic event.

Criterion C: avoidant/numbing

Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma), as indicated by at least three of the following:

1. Efforts to avoid thoughts, feelings, or conversations associated with the trauma.
2. Efforts to avoid activities, places, or people that arouse recollections of the trauma.
3. Inability to recall an important aspect of the trauma.
4. Markedly diminished interest or participation in significant activities.
5. Feeling of detachment or estrangement from others.
6. Restricted range of affect (e.g., unable to have loving feelings).
7. Sense of foreshortened future (e.g., does not expect to have a career, marriage, children, or a normal life span).

Criterion D: hyper-arousal

Persistent symptoms of increasing arousal (not present before the trauma), indicated by at least two of the following:

1. Difficulty falling or staying asleep.
2. Irritability or outbursts of anger.
3. Difficulty concentrating.
4. Hyper-vigilance.
5. Exaggerated startle response.

Criterion E: duration

Duration of the disturbance (symptoms in B, C, and D) is more than one month.

Criterion F: functional significance

The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

Acute: if duration of symptoms is less than three months.
Chronic: if duration of symptoms is three months or more.
With or without delay onset: Onset of symptoms at least six months after the stressor.

Reference: American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders*, 4th Edition Revised. Washington, DC: Author.

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Master Thesis

Article 2:

PTSD in Partners of People with Epilepsy

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Article 2

PTSD in Partners of People with Epilepsy

Abstract

Aims: The objective of the present study was to examine whether living with an individual who suffered from epilepsy was a potentially traumatizing event. This is hypothesized to be the case given the partners' chronic risk of witnessing their loved ones having an epileptic fit, which is characterized by its suddenness and unpredictability, as well as being potentially life threatening. Furthermore, the aim was to identify predictive risk factors in developing posttraumatic stress disorder (PTSD) and thus contribute to the research in PTSD as well as in epilepsy. *Methods:* 614 respondents completed the Harvard Trauma Questionnaire (HTQ), the Crisis Support Scale (CSS), the Hopkins Symptom Checklist-25 (HSCL-25) and the Dyadic Adjustment Scale (DAS). In addition, demographic variables and the consequences of the epilepsy, e.g. severity, frequency and types of attack etc., were assessed in order to identify factors that might predict PTSD. *Results:* 7.7% of the subjects satisfied all three symptom criteria of PTSD and an additional 43.9% reported a subclinical level of PTSD. Thus, well over half of the respondents experienced psychological stress responses. Clinical and subclinical anxiety was unveiled in 9.3% of the respondents and in 2.8% of the partners a similar pattern was found for depression. Even though the partners' experienced psychological distress, the DAS showed that the partners had fine relationship. That is to say that the relationship symbolized an anchor, when the partners struggled with PTSD, anxiety, and depression in advance. *Conclusion:* Partners were at risk of developing PTSD when living with an epilepsy patient. Variables identified that explained PTSD were frequency and types of attack, side effects, and objective and subjective epilepsy, severity, and the HSCL-25. Social support decreased the risk of developing PTSD. The results call for attention to developing interventions for relatives.

Keywords: PTSD, epilepsy, severity, anxiety, depression, social support, intervention

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 patients' point of view focusing on the psychological, physical and social consequences following the illnesses, and few have studied these issues from the partners' position. Partners' well-being is 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 (Nissen, Madsen, & Zwisler, 2008). Specially, support from spouses is considered as being the most helpful and important support for patients (ibid.). 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 are also going to take care of the partners such as public services and the social network. Fortunately, increasing attention is being paid to the impact of chronic illnesses on partners and also family systems as a whole (Rees, O'Boyle, & MacGonagh, 2001), which also is important in light of the fact that significant others often are more distressed than the patients themselves (Couper et al., 2006; Mosher and Danoff-Burg, 2004; Tuinmann et al., 2004). Some of the various consequences to partners who live with chronically ill loved ones are presented below.

Spouses of people with dementia are 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, seemed to be responsible in increasing the stressful response in caregivers. In addition, the perception of heavy burden load and lack of social support resulted in depressive and stressed feelings (Shoenmakers, Buntinx, & Delepeleire, 2010).

Spouses of patients suffering from heart failure (HF) reported feelings of being over burdened, stressed, and depressed. Specifically, the number of caregiving tasks and the perceived difficulty in performing them were risk factors in developing stress and the experience of burden (Saunders, 2003). In addition, Luttik et al. (2007) found that providing personal care to HF patients and the partner's mental health were identified as more important variables to consider.

Finally, caregivers of people with Multiple Sclerosis (MS) reported caregiver burden. Similar with caregivers of people with dementia, the unpredictable character of this illness also increased emotional distress, including the inability to predict the onset of relapse, the progression of the illness, and the patient's functional ability in everyday life (McKeown et al., 2004; Buhse, 2008).

Conclusively, this selection of the literature concerning psychological consequences in close relatives of people with chronic illnesses revealed that the significant others are at potential risk of developing different kinds of psychological distress. However, the experience of being close relatives is not only negative (Sales, 2003). It is important also to note that caregivers were willing to provide care for their loved one and furthermore, it was considered as a natural, expected role (ibid.). Additionally, when caregivers felt involved and supported and were able to cope with the caregiver situation, this lead to better well-being (van Andel et al., 2011; Ohaeri, Awadalla, & Farah, 2009). In line with this, other coping strategies reported were benefit finding and attributing life events to a higher meaning, which has been linked to life satisfaction in caregivers of patients with MS and cancer (Pakenham & Cox, 2008; Kim, Schulz & Carver, 2007). However, strikingly few data are available on the adaptive coping strategies of caregivers (Shoenmakers, Buntinx, & Delepeleire, 2010).

Epilepsy

Another group that experience 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 (Forsgren et al., 2005). In Denmark, 50,000 people suffer from epilepsy, and more than 4,500 individuals are diagnosed with epilepsy every year. The prevalence is high in the first years of living, low at the age 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 (Christensen et al., 2007).

Moreover, epilepsy is viewed as a chronic illness. The frequently cited definition of chronic illness was set forth by Williams (1997), who stated that chronic illness is a medically diagnosed ailment with duration of 6 months or more, which shows little change or slow progression. Adjustment to chronic illness in general is a complex phenomenon that simultaneously affects, and is affected by, multiple interconnected domains in the individual's experience. Stewart, Ross and Hartley (2004) distinguish between four domains: 1) the *biological domain,* which consists of the direct effects of the illness or disability such as pain, fatigue, insomnia, nausea, fever etc., 2) the *social domain,* which consists of the social aspects associated with being ill such as relationship with family, spouse, friend, redefinition of roles, managing isolation, and stigma etc., 3) the *emotional domain,* which includes issues related to self-image, reassessment of values, issues associated with belief system, whether spiritual or non-spiritual, finding personal meaning in the disease, redefining normality etc., and 4) the *behavioral domain,* which includes issues related to health maintenance, e.g. administration of medicine and treatment, lifestyle changes as in diet, habits, symptom monitoring etc.

A fundamental facet of epilepsy is the constant threat of a 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 depending on where in the brain the disturbance takes place. The types that are distinguished between are partial, simple and complex seizures, generalized seizures, unclassified seizures and Psychogenic Non-Epileptic Seizures (PNES). Some seizures are very dramatic with symptoms such as convulsions, breathing stop and loss of consciousness, whereas others are characterized by purposeless and weird actions, and others again appear more discrete (Christensen et al., 2007).

The seizures' effect 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 (Hartlage & Hartlage, 1989). 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) that is associated with health consequences in epilepsy patients are of vital concern of the patients themselves as well as their partners and other close relatives (Wheeles, 2006). To diminish the seizures, lots of epilepsy patients are taking medication. As such, Wheeles (ibid.) found that 70% out of 503 respondents with epilepsy relied solely on medication treatments to control their seizures. Moreover, seizure frequency was also reported in the study of Wheeles (ibid.). Of the 503 epilepsy respondents, 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.

Side effects are common in epilepsy patients as well. Some is related to the illness itself, whereas others are related to the epilepsy treatments and medications. Most of the physical effects are stemming from the epilepsy treatments and medications, although memory loss, migraines, muscle twitches, and pain are associated with the illness alone (ibid.).

Furthermore, epilepsy is expressed in terms of increased levels of depression, anxiety, poor self-esteem, and family dysfunction compared to people without the condition (Jacoby et al., 1996; Baker, 2002). Thus, many epilepsy patients 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 is limiting 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 (Wheeles, 2006). Even though the studies referred to here is concerned with people having epilepsy, there is reason to hypothesize that the partners also are influenced socially and especially psychologically. Therefore, the next section is concerned with research in QOL, depression, anxiety, social and leisure opportunities among others in relation to partners of people with epilepsy, since these diseases are found in epilepsy patients and other caregiver populations mentioned above.

The Psychological Consequences of being a Close Relative of People with Epilepsy

The literature reveals that partners of epilepsy patients 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. (2007) 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. (2011) 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 with those of the epilepsy patients, suggesting that the caregivers' well-being have a spill over effect on the patients' well-being. In contrast, Ohaeri, Awadaila, and Farah (2009) 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. In light of the origin of the study, Sudan, another explanation could be culturally, since religion in this country is of high importance. In such cultures, it may be hypothesized that people attribute life events to a higher meaning in order to better cope with the challenges of being epilepsy caregivers.

Because of the high unpredictability and suddenness of epilepsy, there is reason to believe that anxiety is high among close relatives. In support of this, Thompson and Upton (1992) and Lee et al. (2002) found the highest levels of anxiety among the primary caregivers (defined as taking on the major task of supporting the epilepsy patient) contrary 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 (1992) and Lee et al. (2002) are the only two studies that have examined anxiety and depression alone urging for more research in this area to support their results.

In addition, Lee et al. (2003) found a correlation between perceived lack of seizure control and anxiety and depression. Also, epileptic variables such as age at onset of epilepsy, seizure severity, caregivers' concern, and their perceived lack of seizure control were negative 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 epilepsy patients and their caregivers.

Furthermore, social support is just as important in caregivers of epilepsy patients as it is in other caregiver populations. This is because it is considered a potential buffer against distress and a predictor of psychological well-being in general (Elklit, Pedersen, & Jind, 2001; Cohen & Wills, 1985). However, Thompson and Upton (1992) 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 contrary, Lee et al. (2002) 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.

As in the study of Ohaeri, Awadaila, and Farah (2009) set in Sudan, the culture variable also played a role in the study of Lee et al. (2002), which was conducted in Hong Kong. Here the culture is considered collectivistic and thus characterized by high levels of social support and the ability to stick together in families, which may explain the contrasting findings between Lee et al. (ibid.) and Thompson and Upton (1992).

From a social perspective, Nuhu et al. (2010) found caregiver burden associated with patient's unemployment, long duration of epilepsy, and short seizure-free period. In addition, Thompson and Upton (1992) reported challenges in primary caregivers' social activities and intimate relationships followed by finance.

In sum, caregivers of epilepsy patients, 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 close relatives' lives. Nevertheless, the results are more positive in collectivistic cultures compared to individualistic.

PTSD in Partners of 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. As such, when being a partner of a loved one who suffers from epilepsy, the partner is in a potential risk of *"experiencing, witnessing or confronting events that involve actual or threatened death or serious injury, or a threat to the psychical integrity of self or others"*, as the stressor criterion in the PTSD diagnosis is defined (American Psychiatric Association, 1994). Furthermore, *"being diagnosed with a life threatening illness"* is viewed as a potentially traumatizing event as well (American Psychiatric Association, 1995).

PTSD is already found in caregivers of patients with similar illnesses, namely heart transplantation and implementation of a mechanical assist device followed by heart transplantation. Sudden and unpredictable features with life-and-death consequences also characterize these illnesses. Stukas et al. (1999) investigated levels of PTSD among patients and caregivers and found that 10.5% of the 158 patients had PTSD, and an additional 5% were probable cases. For caregivers, 7.7% met the full criteria for PTSD and an additional

11% were probable cases. The factors predicting PTSD were if participants were females, had a history of psychiatric illness, and had lower social support from relatives.

Dew et al. (2004) studied prevalence and risk factors for depressive and anxiety related disorders in 190 caregivers of heart transplant recipients throughout 3 years. They found that 22.5% suffered from transplant related PTSD (PTSD-T), 31.6% suffered from Major Depressive Disorder (MDD), and 7.3% met the criteria for Generalized Anxiety Disorder (GAD). Risk factors identified in this study were positive lifetime history of psychiatric disorder, greater post-transplant caregiving responsibilities, and a poorer relationship with the patient. Furthermore, caregiver unemployment increased the risk of MDD, and younger age, low sense of personal mastery, and high use of avoidance coping strategies increased the risk of anxiety disorders.

Finally, Bunzel et al. (2008) reported PTSD in the long-term psychological aftermaths in caregivers of patients with implantation of a ventricular assist device (VAD) as bridge to successful heart transplantation. Out of 21 partners, 23% of them met the criteria for PTSD, while none of the patients did. In addition, 2% of the patients and 19% of the partners had mild to moderate depression, and 4% of the patients and 23% of the partners reported mild to moderate anxiety. Bunzel et al. found similar results in their studies from 2007 and 2005, although the study from 2005 only examined PTSD, not anxiety and depression.

Thus, in light of the PTSD criteria and the findings from illnesses with similar characteristics as epilepsy, it is the aim of the present study to examine whether being a partner of a loved one who suffers from epilepsy can be considered a potentially traumatizing event because of the chronic risk of experiencing a sudden epileptic fit. Thereby, expanding research in PTSD to the epilepsy area as well. Furthermore, the aim is to identify risk factors in predicting PTSD, and finally, call attention to professionals in making intervention for epilepsy relatives in addition to the patients.

Methods

The data were collected using a questionnaire survey carried out by the Danish Epilepsy Association. The survey focused on partners of people with epilepsy, a group that up to the present have attracted little attention. It was primarily a sociological survey and thus made research into conditions of life (Bengtson, 2009), but psychological reactions were also included. The present article is mainly concerned with the psychological reactions unveiled by the survey.

Subjects

The sample consisted of 614 respondents, which corresponds to a response rate of 63%. Age ranged from 30 to 89 years (*M* = 53.4; *SD* = 12.8). Gender distribution was 350 females (57%) and 264 males (43%). Those of the respondents who were employed (under the age of 65) accounted for 476 (77.5%). This is below average compared to the rest of the Danish population (82.1%) (Bengtsson, 2009). Finally, 517 (84%) of the respondents were married, and 94 (15.3%) co-habited, both of which correspond to the Danish population in general (ibid.).

Procedure and measurements

The questionnaires were mailed to the members of the Danish Epilepsy Association. One was addressed to the person with epilepsy, and one was addressed to their partners. A number of demographic variables such as age, gender, employment, marital status, income and children etc. were studied. Additionally, the respondents answered questions concerning psychological problems measured by the Harvard Trauma Questionnaire-IV, the Crisis Support Scale, the Hopkins Symptom Checklist and the Dyadic Adjustment Scale.

Symptoms of PTSD were estimated using the HTQ (HTQ; Mollica et al., 1992). The HTQ permits an assessment of whether a person suffers from PTSD by measuring the intensity of the three core symptoms of PTSD, namely intrusion, avoidance, and arousal. The scale has been used extensively in the Nordic countries (Bach, 2003). In the current study, the HTQ was adapted to address whether partners that experience a chronic risk of being exposed to an epileptic fit from their loved ones were experiencing a potentially traumatizing event. The scale consists of 17 items, which correspond directly to the PTSD symptoms as described in the DSM-IV-TR (American Psychological Association, 2000). The items were scored on a 4-point Likert-type scale, ranging from 1 (not at all) to 4 (all the time). Only scores greater than 3 counted for a diagnosis. The original HTQ scale has good reliability and validity as well as the Danish version of the scale (Mollica et al., 1992; Bach, 2003).

The Crisis Support Scale (CSS; Joseph, Andrews, Williams, & Yule, 1992) was used to rate the experience of perceived social support when living with a partner who has epilepsy. The scale consists of 7 items that are rated on a 7-point Likert-type scale, ranging from 1 (never) to 7 (always). The CSS has been used in many trauma studies and has good internal consistency, and also good discriminatory power. Also, Elklit, Pedersen, and Jind (2001) conducted a Danish validation study of 4,213 questionnaires from 11 studies that confirmed the psychometric qualities of the scale.

The Hopkins Symptom Checklist-25 (HSCL-25; Derogatis et al., 1974) was used in the study. The HSCL-25 is a widely used, self-administered instrument designed to measure psychological distress in population surveys, and more specifically for this study, mainly symptoms of anxiety and depression. The HSCL-25 is basically a shortened version of the SCL-90-R with two (anxiety and depression) out of originally nine symptom dimensions (Derogatis et al., 1974). The HSCL-25 consists of 25 items rated on a 4-point Likert-type scale, ranging from 1 (not at all) to 4 (extremely). The average item score calculated by dividing the total score of the number of items answered (ranging between 1 and 4) is often used as a measure of distress. For this purpose, the HSCL-25 has proved to have satisfactory validity and reliability (ibid.).

Finally, the Dyadic Adjustment Scale (DAS; Spanier, 1976; Sharpley & Rogers, 1984), a self-administered instrument, was used in the present study to assess the quality of marriage and other similar dyads. More precisely, the four empirically verified components are dyadic satisfaction, dyadic consensus, dyadic cohesion, and affectional expression. Together they constitute the four subscales. The DAS consists of 31 items plus one global item of "overall happiness", which are summed to obtain an overall marital functioning score. A high score indicate higher levels of satisfaction, and scores range from 0 to 151. Moreover, the subscales differ in length, and the items have different response format with the majority rated on Likert-type scales, but also a dichotomous scale is used. The DAS has well-established psychometric properties. The total DAS scale has demonstrated adequate content and construct validity. To date, research generally supports the internal consistency of three of the four subscales, the exception being affectional expression (Graham, Liu, & Jeziorski, 2006).

Results

Statistics

Data were analyzed using SPSS. Statistical tests included descriptive analyses performed on the data using mean scores, standard deviation (SD), and percentages.

The first part is concerned with linear regression analyses to assess the predictive power of the variables HTQ and HSCL-25. Before making the analyses, the variables frequency and types of attack, side effects, and objective and subjective epilepsy were computed. Subjective epilepsy is defined as the partner's fear of a seizure, whereas objective epilepsy is characterized as the seizure per se (Bengtsson, 2009).

Thus, the three HTQ symptom clusters were entered into a linear regression analysis as the dependent variable to establish how much of the PTSD variance that could be explained by the predictors (Table 1). The predictors entered were gender, years of education, unemployment, frequency of attacks, types of attack, side effects, and objective and subjective epilepsy, severity, fear of consequences, and the DAS (model 1). Furthermore, to establish a stronger predictive result, the DAS was replaced with the CSS and the HSLC-25 (model 2).

Next, to establish how much of the PTSD variance that could be explained by the predictor anxiety symptom dimension from the HSCL-25 alone, the three HTQ symptom clusters were entered into a linear regression analysis as the dependent variable (model 3). Afterwards, gender, years of education, unemployment, severity, fear of consequences and the CSS were added together with the anxiety symptom dimension from the HSCL-25 as the predictor variables, and the HTQ as the dependent variable in order to determine a stronger predictive result (model 4).

Table 1
Summary of Linear Regression Analysis for Variables Predicting PTSD (N = 634)

Variable	ΔR^2	B	SE B	ß	t	P
Model 1						
	.141					
Gender		-1.77	2.54	-.10	-.70	.490
Education		-.82	.96	-.12	-.85	.399
Unemployment		-1.16	1.22	-.13	-.95	.349
Computed variables		.93	2.43	.07	.38	.705
Seizure severity		2.47	1.48	.32	1.67	.103
Fear of consequences		.12	.31	.06	.39	.705
DASconsens		.24	.24	.16	1.01	.318
DASsatisfa		.20	.46	.06	.42	.674
DAScohesion		-.47	.35	-.19	-1.33	.192
DASAffexpre		1.24	.94	.19	1.31	.196

Model 2						
	.512					
Gender		-2.08	1.37	-.11	-1.52	.132
Education		.72	.49	.10	1.47	.144
Unemployment		.56	.60	.07	.93	.354
Computed variables		-2.44	1.22	-.17	-2.00	.048*
Seizure severity		2.03	.68	.25	2.98	.004*
Fear of consequences		.06	.16	.03	.39	.696
CSS		-.24	.09	-.19	-2.53	.013*
HSCLTotal		.48	.06	.59	7.54	.000**
Model 3						
	.320					
Suddenly afraid without reason		2.92	.81	.17	3.59	.000**
Feeling of tension or of being nervous		2.87	.63	.21	4.60	.000**
Restlessness/impatience		2.65	.59	.19	4.45	.000**
You feel anxious		2.80	.79	.17	3.56	.000**
Model 4						
	.515					
Gender		-1.72	1.31	-.09	-1.31	.192
Education		.73	.48	.11	1.55	.125
Unemployment		.45	.57	.06	.79	.430
Seizure severity		3.87	1.39	.19	2.79	.006*
Fear of consequences		.82	1.26	.04	.65	.518
CSS		-.37	.09	-.31	-4.37	.000**
HSCLAnxiety		1.18	.15	.56	7.64	.000**

Note: Dependent variable: HTQTotal. DAS = Dyadic Adjustment Scale. CSS = Crisis Support Scale. HSCL = Hopkins Symtom Cheklist-25.
* *p* < .05. ** *p* < .001.

The second part is concerned with Pearson's correlation analyses between the HTQ, the HSCL-25, and the DAS, and also between the DAS and the question about the experience of overall happiness in life. This way, the aim was to gather information of how PTSD, the symptom dimensions anxiety and depression, and the overall feeling of happiness in life influenced on marriage.

Table 2
Intercorrelations between Subscales for Dyadic Adjustment Scale, PTSD, Anxiety, Depression, and Happiness

	HSCL-25	HTQ	Happiness	DASconsens	DASsatis	DAScohesion	DASAffexpre
HSCL-25							
HTQ	.632**						
Happiness	-.282**	-.231**					
DASconsens	.335**	.205**	-.294**				
DASsatisfa	.323**	.221**	-.175**	.497**			
DAScohesion	.182**	.096*	-.120**	-.311**	-.193*		
DASAffexpre	.179**	.109*	-.181**	.057	.234**	-.056	

Note: * $p < .05$. ** $p < .001$ (2-tailed).

HTQ

Out of 634 partners, 43 (7.7%) met all the criteria for a full PTSD diagnosis. With regards to the subclinical levels, those who met the criteria for intrusion accounted for 129 partners (23.2%), and 115 partners (20.7%) met the criteria for arousal. 268 persons (48.3%) did not report any symptoms, and data from 79 persons (7.7%) were missing. Thus, together the results revealed that well over half of the partners reported psychological stress responses.

Gender, years of education, unemployment, frequency of attacks, types of attack, side effects, and objective and subjective epilepsy, severity, fear of consequences, and the DAS did not account for much of the variance (14.1%) in explaining PTSD ($F = 1.87, p \leq .005$) (model 2). When the DAS was removed and replaced with the HSCL-25 and the CSS, the variables explained 51.2% of the variance ($F = 14.63, p \leq .005$) in the development of PTSD. The results showed that the HSCL-25 was strongly significant which implies that psychological distress such as anxiety and depression explain the variation of PTSD severity well. Social support had a positive effect on PTSD, meaning that when the partners experienced increased support the risk of developing PTSD fell. The results also showed that the severity of the epilepsy is an important variable in explaining PTSD, meaning that the risk of developing PTSD increased with the severity of the epilepsy. A similar pattern was found with regards to the frequency and type of attack, side effects, and objective and subjective epilepsy that entailed a negative effect in explaining PTSD (model 3).

HSCL-25

The two category symptoms anxiety and depression in the HSCL-25 were assessed individually to measure the frequency. The cutoff point was ≥ 1.75 for clinical anxiety and depression, whereas the cutoff point was ≥ 1.55 for probable cases. This means that the validity coefficients obtained by the HSCL-25 in this study were comparable to those obtained in other studies (Nettelbladt et al., 1993). Out of 634 partners, 22 (3.8%) met the criteria for clinical anxiety (HSCL-25; mean ≥ 1.75). A subsample of 31 persons (5.5%) was screened as probable cases (HSCL-25; mean ≥ 1.55). Individuals who met the criteria for clinical depression accounted for 18 persons (2.8%) out of 634 recipients.

When the frequency of anxiety was higher compared to depression, the anxiety symptom dimension from the HSCL-25 alone was entered into the regression analyses. The variance accounted for 32% ($F = 63.8$, $p \leq .001$) in explaining PTSD with all the anxiety questions significant (model 3). Adding the variables gender, years of education, unemployment, severity, fear of consequences, and the CSS, they together explained 51.5% of the variance ($F = 17.4$, $p \leq .001$). Social support and the anxiety symptoms in the HSCL-25 explained PTSD very well ($p < .001$). The variable severity was close to significant ($p < .006$) (model 4).

DAS

Finally, the correlation showed a significant result between PTSD, the anxiety and depression clusters stemming from the HSCL-25, and how couples adjust to each other with reference to the DAS. Also, a significant correlation was found between the scale of how well couples adjust to each other and the question concerning happiness *"If you think at your life at the moment, how happy or unhappy do you feel?"* (Table 2).

Discussion

The overall focus of the present study has been to examine whether partners that experience a chronic risk of being exposed to an epileptic fit of their loved ones were experiencing a potentially traumatizing event. The results supported the hypothesis, showing that the partners were at risk of developing PTSD, with 7.7% of the subjects satisfying all three symptom criteria of PTSD and an additional 43.9% found to be at a subclinical level of PTSD. These results are in accordance with those of Bunzel et al. (2005; 2007), who studied PTSD in partners of patients who were having a VAD.

The results from the linear regression analyses showed that gender, years of education, unemployment, frequency and types of attack, side effects, and objective and subjective epilepsy, severity, fear of consequences, social support, and anxiety and depression together made up for 51.2% of the variance in explaining PTSD. Particularly, psychological distress such as anxiety and depression were strong variables in explaining PTSD. Also, severity, frequency and types of attack, side effects, and objective and subjective epilepsy played a significant role in explaining PTSD. The results are consistent with the findings of Lee et al. (2003) that found a negative correlation between seizure severity and psychological adjustment. In addition, Lane et al. (1998) found that seizure control played a role in burden, because a small number of patients continued to have seizures postsurgery, which affected the caregivers who endorsed higher levels of burden.

In contrast, the results from Luttik et al. (2007) studying caregiver burden in HF patients revealed that patient's disease severity was not related to caregiver burden. Instead, the partner's own mental health and providing personal care to HF patients were identified as more important variables to consider. This is supported by Whestpal-Guitti et al. (2007), who also found low scores in mental health of the caregivers. Of note, no studies have yet studied variables that may predict PTSD, which makes it difficult drawing direct comparison to the present study.

On contrary, the present study found that social support had a positive effect in explaining low levels of PTSD, indicating that when a partner experienced social support from his or her surroundings this counteracted the tendency to develop PTSD. This is in line with the assumption that social support is a buffer against psychological distress (Elklit, Pedersen, & Jind, 2001; Cohen & Wills, 1985). Furthermore, the results are supported by Thompson and Upton (1992), who found that low level of social support increased the risk of psychological strain.

Additionally, the present study found a prevalence of anxiety and depression with the majority reporting anxiety (9.2%), whereas depression accounted for 2.8%. The variables gender, years of education, unemployment, severity, fear of consequences, social support, and anxiety and depression explained 51.5% of the variance. Social support, anxiety and depression were extremely significant and as such explain PTSD very well. The results are in accordance with Thompson and Upton (1992) and Lee et al. (2002) who found higher levels of anxiety than depression in epilepsy caregivers. The same results were found in the studies of Bunzel et al. (2007; 2008). Anxiety and depression is often seen as co-morbid diagnoses together with PTSD. In fact, it is the exception rather than the rule for individuals to meet diagnostic criteria for PTSD in the absence of meeting criteria for another psychiatric disorder (Yehuda & McFarlane, 1995).

Finally, the present study found the partners experienced their marriage or relationship as an anchor given the circumstances of their lives. As such, there was a tendency to stick together when they struggled with anxiety, depression and PTSD in advance. Previous studies have investigated an illness' impact on relationships with diverging results. For instance, Thompson and Upton (1992) found that caregivers of epilepsy patients reported problems in intimate relationship, although this study resulted in the opposite result with fine dyadic adjustments. Furthermore, when interpreting the results by van Andel et al. (2011) concerning the spill over effect of caregivers' HRQOL on patients' HRQOL, there is reason to believe that by increasing caregivers' HRQOL a better dyadic relationship between caregiver and patient may be observed. However, further research is needed to establish which factors diminish and enhance the feeling of well-being in dyadic relationships.

In sum, living with a loved one who suffers from epilepsy is potentially traumatizing in that the partners experience a constant dread of when their loved ones will have an epileptic fit. The traumatic aspect is twofold and includes both the witnessing of a seizure and the heightened anxiety, fear, and worry as they attend to their sick family member. Furthermore, the impression is reinforced by gender, years of education, unemployment, the severity of the epilepsy, frequency and type of attacks, side effects, and the objective and subjective experience of the epilepsy. This is in line with the findings from Thompson and Upton (1992), Lee et al. (2002), and van Andel et al. (2011) among other studies mentioned earlier. All in all, that characterization corresponds well to the PTSD diagnosis. What counteract the development of PTSD are social support and the couples' ability to adjust to each other, which instead enhance social well-being.

Nevertheless, some of the variables are worth noticing, namely seizure severity, fear of consequences, and socioeconomic variables. First, seizure severity and fear of consequences were identified variables in explaining PTSD, although only severity was significant. In line with this, it is reasonable to hypothesize that seizure control independent of severity may be important to consider in light of the development of PTSD and as such may influence on fear of consequences as well. Therefore, if caregivers are aware of preseizure activity and are able to prevent seizures or reduce them, this must give an experience of being in control. This will in turn diminishes the risk of developing psychological stress. The explanation seems logical; the more people feel in control of events, the less helpless they are, and as such believe that similar future events can be avoided. In support of this, Updegraff and Taylor (2000) found that perceived control over traumatic events were a protective factor against depression and posttraumatic stress syndrome (PTSS). Regarding epilepsy, Lee et al. (2002) found that caregivers' perceived lack of control was correlated with their negative psychosocial adjustment. These findings signify that achieving better control of seizures is a vital key to improving the QOL in both epilepsy patients and their caregivers. Furthermore, Pinikahana and Dono (2009) actually did found in their study that 74% of caregivers were aware of initial symptoms of epileptic seizures. Furthermore, the most commonly reported triggers were stress, tiredness, and sleep deprivation. Half of the responding caregivers were able to tell when a seizure was about to occur, and 15.4% was able to prevent a seizure by using techniques such as relaxation, resting and medication. In spite of this, further research is needed that focus on whether the ability to identify and prevent a seizure by the caregivers decrease the risk of developing psychological stress.

Second, years of education and unemployment were identified as some of the variables that explained the development of PTSD. Not surprisingly, participants with better socioeconomic position would be less prone to develop PTSD. Individuals with many social resources for instance given years of education and being employed, including social support and having primary confidants as well, were better prepared to cope with distressful events (Thompson & Upton; Hobfoll, 1991).

Overall, the predictive power in the study were not overwhelming high regarding the variables that influenced on PTSD. To increase the result, the study also could have focused on coping strategies, attachment styles, and cognitive patterns. Then an estimated predictive power would probably increase. In addition, it will give a broader perspective of the traumatic events due to living with a loved one, who suffers from epilepsy.

In order to broaden the perspective additionally, Stukas et al. (1999) found PTSD in both partners and patients. Hence, it is interesting screening for PTSD not only in the partners, but also their loved ones with epilepsy, including screening for anxiety and depression as well. Thereby, it is possible to make comparison between the two groups and generalize to similar illness groups such as the study of Stukas et al. (ibid.).

Furthermore, the review by Tedstone and Tarrier (2003) shed light on the importance of studying PTSD in illnesses similar with epilepsy characterized by the features as sudden, unexpected and potentially life threatening. Of note, the authors ended up concluding that it seemed that the close relatives were even more traumatized than the patients themselves, which is in line with the results reported by Couper et al. (2006), Mosher and Danoff-Burg (2004) and Tuinmann et al. (2004) that the significant others often are more distressed than the ones with the illness. Thus, in light of this future research is twofold. That is to say to expand research concerned with not only PTSD in partners of people with epilepsy, but also the epilepsy patients themselves. Second, to expand research that study PTSD not only in patients with similar illnesses as epilepsy but also the partners.

Limitations of the Study

Notwithstanding, the results should be treated cautiously since the study has a number of limitations. Firstly, 1221 were asked to fulfill the questionnaire, and of those 614 responded. This is interesting since some studies report that non-respondents often are more distressed, suffer from PTSD, and the resources are fewer to participate (Weisaeth, 1989; Holen, 1990). As a consequence, this could lead to an underestimation of PTSD in the partners, if assuming that the level of traumatized individuals would be significant in non-respondents as well (Schut et al., 1991). With regard to the number of the respondents, the power of the study is good. This is in contrast to the studies of Bunzel et al. (2005; 2007; 2008) that had a rather small sample size.

Secondly, the ability to draw comparisons to similar results from other studies of epilepsy caregivers is limited, since this is the first study of its kind. Therefore, further research is needed to confirm the results from the present study.

Thirdly, the self-report method could have produced a response bias with some subjects evaluating their situation either more positively or more negatively. The potentially traumatic events the partners experience in living with a loved one who has epilepsy, might also be a bias concerning the subject's ability to stay factual and honest because of their unwillingness to remember the painful experiences. Moreover, it could be interesting if baseline data were available, because pre-traumatic vulnerability may have given rise to psychological mechanisms affecting the traumatic response. However, such data are very difficult to establish conclusively for methodological reasons.

Finally, when doing a Cronbach's alpha analyses, the questions concerning QOL from the survey had too low internal consistency to be used in the study. To overcome this, questions relating to well-being can be measured by the SF-36 that focus on health status on 8 dimensions: physical functioning, physical role, emotional role, social functioning, mental health, bodily pain, vitality, and general health. In addition, comparisons between this study and van Andel et al. (2011) would have been possible.

Clinical Relevance

In a third of all trauma cases, PTSD has been shown to be a disorder that may become chronic and develop co-mobidity with other psychological diseases such as general anxiety and major depression (Kessler et al., 1995). Consequently, the results of the present study point out several implications for clinical practice.

Some of the significant variables in explaining PTSD severity found in the present study may be evident already at the onset of the loved one's epilepsy or before the couple met each other. For instance if the partner have had stress earlier in life or struggled with other mental health problems. Therefore, these variables provide potential markers for early intervention and support in order to prevent the development of PTSD and other adverse psychological sequalae in the partners. The results of the study suggest that consideration of the outcome and well-being of partners of people with epilepsy is an important task to all professionals in contact with these persons at a time of heightened psychological vulnerability.

It is desirable if the results also could contribute to decisions about selection of screening instruments as useful tools for health care personnel and private practitioners. Assessing risk factors not only in those who suffer from epilepsy but also their partners would allow professionals to allocate resources and services to those at the greatest risk of developing PTSD. In addition, a comprehensive assessment would allow the selection of the most appropriate treatment options (Nissen, Madsen, & Zwisler, 2008).

Finally, educating partners of individuals with epilepsy that their reactions are expected and consistent with research findings will enable them as well as their surrounding environment to accept their reactions and better understand how it is to witness a loved one having a chronically illness and the consequences that follow for both parties. In line with making interventions such as educating partners, van Horn et al. (2002) obtained positive effects of intervention programs. The positive effects consisted of improved QOL, perceived control in everyday life, and the enhancement of coping strategies. On the other hand, these invention programs decreased anxiety in patients as well as in partners. Also, positive consequences were found concerning the social network and confidence in the partner. In addition, the study of van Andel et al. (2011) found that caregivers' HRQOL had a spill over effect of the patients' HRQOL. This all in all yield for the fact that partners and close relatives are a resource that need to be taken care of in order to maintain psychological well-being.

In spite of this, research has shown that health service interventions targeting the relatives are sparse. Therefore, hospital departments and other helpful instances need practical information and concrete examples of what to do and how to establish activities for relatives. As such, testing a variety of activities and, on that basis, it is possible providing guidelines for effective activities for the relatives (Nissen, Madsen, & Zwisler, 2008).

Conclusion

Closing, the article's purpose was twofold. Firstly, the study found PTSD in partners of people with epilepsy given the illness' unpredictable character. Both witnessing a loved one having a seizure and living with the constant fear of when a seizure might occur is especially traumatizing features. Specifically, 7.7% of the subjects satisfied all three symptom criteria of PTSD, and an additional 43.9% reported a subclinical level of PTSD. Variables that explained PTSD were frequency and types of attack, side effects, and objective and subjective epilepsy, severity, and anxiety and depression. Social support decreased the risk of developing PTSD. Clinical and subclinical anxiety was unveiled in 9.3% of the respondents, and in 2.8% of the partners a similar pattern was found for depression. Finally, it seemed that the partner and the epilepsy patient's relationship were fine, and thus it symbolized an anchor, when one part struggled with epilepsy and the other part with PTSD, anxiety and depression in advance.

However, since the study is the first of its kind, further research is needed to support the results. In addition, the article calls for attention to professionals yielding for intervention not only in epilepsy patients but also in the close relatives. This is also in light of the spill over effect of caregivers' HRQOL to the patients' HRQOL. In line with this, suggestions for future research were raised regarding (1) studying PTSD in both patients and caregivers also to make comparison between the two groups and thereby generalize to similar illness groups, (2) studying whether the ability to identify and prevent a seizure by the caregivers decrease the risk of developing psychological stress, and (3) examine and support the results by Tedstone and Tarrier (2003) in depth including investigate the impact on the close relatives to expand the prevalence of PTSD even broader. A step was taken in this article by expand PTSD to epilepsy partners, which was the second purpose of this article.

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