



Self-reported anxiety and sleep problems in people with epilepsy and their association with quality of life



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ABSTRACT

Comorbidities are common in epilepsy, and their role in quality of life (QOL) is receiving increasing scrutiny. Considerable attention has been focused on the role of depression, the most common comorbidity, with rather less attention paid to its frequent concomitant, anxiety, and other conditions known to be at increased prevalence among people with epilepsy (PWE) when compared to the general population. In this paper, we report findings from a UK-based survey in which we examined self-reporting of two common comorbidities, anxiety and sleep problems, factors associated with them, and their role in QOL in people with and without epilepsy.

Data were obtained via mailed questionnaires, supplemented by an internet survey, from PWE and age- and gender-matched controls. Based on self-reported symptoms, PWE were at higher risk of anxiety and sleep problems. Contributory factors for anxiety included poorer general health, worry about seizures, and self-reported antiepileptic drug (AED) side effects. Good social support emerged as protective for anxiety in PWE. Nighttime sleep problems were very common even in controls but were further elevated in PWE. Antiepileptic drug adverse events emerged as an important contributory factor for sleep problems. Trait anxiety emerged as significant for defining overall QOL, and its importance over state anxiety supports the notion of anxiety in PWE as a primarily premorbid condition. In contrast, sleep quality was not consistently predictive of QOL. Our study has important implications for clinical management, emphasizing the need for a holistic approach to address wider patient-reported problems as well as any epilepsy-specific ones.

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1. Introduction

A diagnosis of epilepsy can have major negative implications for an individual's quality of life (QOL) and be associated with an increased risk of psychological problems [1,2]. To date, the most commonly explored factor implicated in reduced QOL of people with epilepsy has been seizure frequency: it has been reported that the vast majority of individuals who enjoy seizure freedom do not have lower QOL scores in comparison to the general population [3–5] while for those continuing to experience seizures, their QOL can be severely adversely affected [6]. Jacoby et al. [7] reported that in patients with new-onset seizures treated with antiepileptic medication, 2-year QOL profiles were enhanced compared to baseline for patients experiencing a single seizure only or entering an early remission and further impaired for patients experiencing late remission or a relapse to seizures. Spenser et al. [8] reported similar patterning of QOL among patients with epilepsy treated surgically, some of whom remained seizure-free subsequently

while others experienced a recurrence of seizures. Seizure freedom, then, has been shown to reduce the 'intrusiveness' of epilepsy for QOL [9]; however, among potentially relevant clinical variables, seizure frequency alone has not been able to adequately account for observed impairments in QOL. Other potentially important predictors of QOL scores include seizure severity [10], seizure type [11], type of epilepsy [12], and treatment-related side effects [6,13].

While it is undeniable that its clinical features can have a major impact on QOL, a more recent alternative line of enquiry has aimed at examining the effects of the various comorbidities associated with having epilepsy. Strine et al. [14] reported on the prevalence of psychological and physical comorbidities in a large community sample in the US. Psychological distress including serious mental illness and major physical health problems were both more commonly reported by individuals identifying themselves as having a history of seizures than by nonaffected individuals as were other markers of impaired QOL such as not being in employment. Pulsipher et al. [15] reported a significant association between decreasing overall QOL and physical and psychological comorbidities, with these jointly accounting for around 14% of the variance in QOL scores. The differential effects of the different types of comorbidity were also highlighted by these authors – comorbid

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psychological conditions being more strongly predictive of scores for life satisfaction, epilepsy-related effects, and cognition and medical comorbidities being more strongly predictive of physical function and role limitations.

Anxiety and depression are the most commonly reported psychological problems among individuals with epilepsy [1,15–18]. For example, in the US 2004 HealthStyles Survey [18], those classifying themselves as having been affected by epilepsy were also twice as likely to report anxiety or depression as were other respondents and those classifying themselves as having active epilepsy were three times more likely to do so. Johnson et al. [19] set out to investigate the impact of anxiety and depression, as markers of psychological well-being, on health-related QOL and found that both exerted negative impacts. Furthermore, anxiety and depression emerged as more powerful predictors of QOL scores than did seizure frequency and severity. Similarly, Cramer et al. [20] found that both anxiety and depression significantly reduced QOL scores and the more severe they were, the more effects were noted on QOL measures.

However, it should be noted here that estimates of the incidence of both these psychological problems have varied widely [16,17,21,22]. Further, it is recognized that rates of psychological comorbidity are likely underestimated since an individual may be experiencing problems that are not made evident to the clinician. O'Donoghue and colleagues [23] found that only a third of those who could be classed as experiencing definite or borderline anxiety or depression based on their responses on a self-reported measure had psychological symptoms reported in their medical files.

Historically, much less attention has been given in the literature on epilepsy and QOL to prevalence and impact of anxiety problems than to depression [24]. For example, in a textbook published in 2000 on 'problem-solving in clinical practice', Schmitz [25] addresses the management of psychoses, depression, and suicidal behavior but not that of anxiety problems. In the context of epilepsy, anxiety may exist in its own right or be related to chronic features of epilepsy, be experienced only as part of a seizure, or be a more long-standing problem and patients can have symptoms which would fall under the category of generalized anxiety – persistent worrying about relatively minor matters [26].

Jacoby and colleagues [1,4] found that self-reported anxiety levels in a large community population of PWE differed markedly according to seizure frequency and correlated strongly with other QOL measures such as perceived impact of epilepsy and felt stigma. De Souza and Salgado [27] found levels of anxiety to be unrelated to either epilepsy or treatment variables or sociodemographic characteristics such as gender. It has been noted [28] that as in the general population, individuals with epilepsy may have varying susceptibility to developing psychological disorders such as anxiety. Johnson et al. [19] have cautioned that the emphasis that has been seen on depression in epilepsy should not eclipse the important role of anxiety for QOL of people with epilepsy since it exerts its own independent effects. In their own study, self-reported anxiety accounted for more than 30% of the variance in QOL scores (similar to the amount of the variance explained by self-reported depression) and independently predicted QOLIE-89 cognitive, physical health, and mental health subscale scores.

Sleep complaints are a frequent concomitant of anxiety disorder [29], and compromised sleep is known to be common among PWE [30,31]. Interactions between epilepsy and sleep have been found to take a number of different forms, including delay in sleep onset, difficulty staying asleep, or waking up too early [31], and have been associated with a number of potential causes, including insufficient sleep syndrome, poor sleep hygiene, coexisting sleep disorders, the effects of seizures themselves, and the effects of AEDs [32]. A large study by De Haas and colleagues [33] showed that over a 6-month period, PWE had twice the prevalence of subjective sleep disturbance as controls and that the presence of sleep disturbance was associated with a significant reduction in QOL beyond that attributable to just having epilepsy.

In the general population, sleep disturbance creates huge demand for health-care services and huge use of over-the-counter medication [34]. Importantly, sleep disorders may also be indicators of major anxiety and depression [35].

Though Hermann [36] included sleep in his list of key domains of QOL for PWE, far less attention has been paid by researchers to this aspect of living with epilepsy than to anxiety or depression. As a result, the literature remains sparse and contradictory – despite that the role of sleep problems in impaired QOL is highlighted by patients with epilepsy themselves as are their concerns over the possibility that drug treatment may create or exacerbate problems with sleep [37]. Such concerns appear justified by a small but convincing literature identifying the quite differing effects that AEDs can have on sleep quality [31,32]. It has been argued that, like anxiety, sleep problems which are common in PWE are frequently missed by clinicians [32]. Sleep problems appear particularly common in patients experiencing partial seizures [33,38,39]. Both excessive daytime sleepiness [40,41] and obstructive sleep apnea [41] have been found to be more frequent in patients with epilepsy than in neurology patients without epilepsy and the general population.

That the complex relationship between epilepsy and anxiety and its frequent concomitant, sleep complaints, requires further investigation was the starting point for the work reported here. The overall aim of the study was two-fold: to examine rates of self-reported anxiety and sleep problems in people with epilepsy (PWE) and to explore contributory factors. Specifically, our objectives were as follows:

- i. To compare levels of self-reported anxiety and sleep problems in PWE with those in controls to gain appreciation of the size of the problem in this patient group;
- ii. To define the nature and extent of self-reported anxiety and sleep problems in two separate cohorts of PWE;
- iii. To investigate the relationship of self-reported anxiety and sleep problems to a range of epilepsy-related and other factors;
- iv. To identify from a broad range of possible predictors the most powerful predictors of anxiety and sleep problems reported by PWE;
- v. To explore the relationship between anxiety and sleep problems and overall QOL in PWE.

2. Methods

2.1. Data collection strategies

A postal approach was used for data collection. The advantages of such an approach are well rehearsed in the literature [42], and we had successfully used it for collection of QOL information, including measures of psychological distress, previously [3,4,6,43–45]. People with epilepsy were recruited from two separate sources: the patient database of a large tertiary care center for epilepsy in North West England and the membership database of the UK national patient organization, Epilepsy Action (EA). To maximize recruitment from the EA sample (since previous work suggested that it might be less easy to recruit), the postal approach was supplemented by two other approaches described below.

2.2. Details of measurement instruments included in patient and control questionnaires

Two separate self-completion questionnaires were developed – one for people *with* and one for people *without* epilepsy – using previously validated scales, as detailed in Table 1, to ascertain for all respondents the presence/absence of anxiety disorder, daytime and nighttime sleep problems, degree of social support, overall health status and any (other) long-term health problems, and sociodemographic status (as described by age, gender, educational and occupational status). Additionally, the PWE questionnaire contained questions about possible medication side effects, worry about seizures, and perceived impact

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