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Social anxiety and its psychosocial impact on the lives of people with epilepsy

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ABSTRACT

Little is known about social anxiety among people with epilepsy (PWE), although PWE are more likely to be diagnosed with social anxiety disorder than the general population. The purpose of this study was to determine which psychosocial and seizure-related variables are associated with social anxiety. It was hypothesized that social anxiety would be positively correlated with perceived seizure severity, stigma, impact of epilepsy, fear of negative evaluation, and experiential avoidance. Further, social anxiety would be negatively correlated with epilepsy knowledge and disclosure of epilepsy. Finally, if a seizure occurred in public and others were unaware of the epilepsy, participants would report greater judgment, anxiety, and rumination compared with those in a situation where others were aware of the epilepsy. A total of 101 individuals with epilepsy participated in this online study. Social anxiety was found to correlate with both psychosocial and seizure-related variables in the expected directions. Further, social anxiety predicted significant variance in stigma and disclosure beyond known predictors of stigma. Participants in both conditions (disclosed diagnosis of epilepsy versus undisclosed diagnosis of epilepsy) were equally distressed by having a seizure in public. These findings provide an initial basis for discerning how to best assess and support PWE with social anxiety.

1. Introduction

Epilepsy affects more than fifty million people worldwide [1]. In addition to seizures, psychopathology is often experienced by people with epilepsy (PWE) [2]; however, it is usually not identified or treated [3]. Although much of the research into psychopathology among PWE has focused on depression [4], more attention has begun to be given to the investigation of anxiety [e.g., 5]. Generalized anxiety disorder, obsessive–compulsive disorder, panic disorder, and posttraumatic stress disorder have been studied among PWE [6]; however, social anxiety disorder has not been thoroughly addressed in the literature. Co-occurring anxiety is associated with lower quality of life for PWE [e.g., 7,8], and it is likely that this is also true for comorbid social anxiety.

1.1. Social anxiety and epilepsy

Prevalence rates for lifetime mental health disorders among PWE range between 25.9% and 44.0%, which is higher than the general population (19.5%–20.7%) [9]. Furthermore, the prevalence rate for lifetime anxiety disorders for PWE is 22.8%, while it is only 11.2% for the general population. People with epilepsy have been shown to be five times more likely than the general population to be diagnosed with social anxiety, with an odds ratio higher than other anxiety and depressive disorders [2]. People with epilepsy are also more likely to have social anxiety when compared with individuals with other chronic disorders [2].

Social anxiety is a "marked fear or anxiety about one or more social situations in which the individual is exposed to possible scrutiny by others" [10, p. 202]. Individuals with social anxiety are overly concerned with the possibility of humiliating or embarrassing themselves in social situations and, consequently, being negatively evaluated by others. To avoid being negatively evaluated, people with social anxiety closely monitor what they do, which may lead them to engage in safety behaviors to mitigate their anxiety [11]. For PWE, a safety behavior may be nondisclosure of their epilepsy diagnosis or avoidance, as demonstrated by not acknowledging fears associated with seizures or simply not thinking about their condition [12].

Few research studies have been conducted to examine social anxiety among PWE, and even less has been conducted to assess how psychosocial and seizure-related variables are associated with these elevated levels of social anxiety among PWE. There is one incidental finding in regard to social anxiety among PWE. Baker, Spector, McGrath, and Soteriou [13] assessed the impact of epilepsy on the lives of adolescents

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in the United Kingdom and found that lower levels of epilepsy knowledge were associated with higher levels of social anxiety. Therefore, there is much that remains unknown about social anxiety among PWE and how their lives may be affected by it.

Social anxiety among PWE may also influence stigma associated with epilepsy, especially given the significant fears of negative evaluation by others inherent in this condition. Stigma is often experienced by PWE [14], given that epilepsy is a disorder that has been greatly misunderstood in the past and continues to be misunderstood today [15]. Enacted stigma is defined as the actual, overt events of discrimination against an individual or group, whereas felt stigma is defined as the shame associated with having epilepsy coupled with the fear of enacted stigma [14]. Jacoby [16] found that felt stigma was related to a variety of factors, including anxiety, depression, and seizure severity. In addition, felt stigma varied according to seizure frequency, with felt stigma being reported by only 14% of PWE who had stable epilepsy compared with 51% of PWE with frequent seizures [16]. Furthermore, Baker et al. [13] demonstrated that anxiety, impact of epilepsy, age, and seizure frequency predicted stigma among PWE. Social anxiety may predict stigma beyond these variables and depression, as the more social anxiety an individual has, the more likely it is that he or she will perceive that others are treating him or her differently. It may also be the case that the direction of this relationship is the opposite, that is, the more stigma an individual with epilepsy perceives, the more likely he or she is to experience symptoms of social anxiety, similar to the findings of Peterson et al. [17], who found that anxiety (among other variables) was a significant predictor of stigma among PWE.

Individuals high in social anxiety are less likely to self-disclose personal information [18]; therefore, it is likely that social anxiety is related to the degree to which PWE disclose their epilepsy diagnosis. Over half of the participants in Westbrook, Bauman, and Shinnar's [19] study kept their epilepsy diagnoses from other people, and 70% never talked about it. This concealment of epilepsy may be related to social anxiety, as PWE may fear being negatively evaluated for having the condition. Tonic–clonic seizures, frequency of seizures, and longer duration of epilepsy did not predict the degree to which individuals disclosed about their disorder [19]. Interestingly, Westbrook et al. [19] also found that stigma did not predict disclosure. Perhaps social anxiety or the fear of negative appraisal, rather than stigma, is a better predictor of the degree of disclosure. People with epilepsy who fear a negative reaction or differential treatment from others may choose not to tell others about their condition and may be fearful that others may find out about their epilepsy in social situations. Similar to the relationship among social anxiety and stigma related to epilepsy, the direction of this association is ambiguous. Low disclosure of an epilepsy diagnosis may cause an individual to experience greater social anxiety.

1.2. Psychosocial variables, anxiety, and epilepsy

The presence of anxiety negatively affects the lives of PWE, and various studies have been conducted to assess which psychosocial and seizure-related factors are associated with anxiety in general among PWE [20]. In a recent study of Jordanians with epilepsy, quality of life was found to be negatively affected by increased seizure severity and psychosocial factors, such as depression and anxiety [21]. Additionally, Baker, Jacoby, and Chadwick [22] also found that individuals with higher levels of anxiety reported that epilepsy had a greater impact on their lives. Further, social factors, rather than seizure-related variables, accounted for the majority of the variance in the individuals' psychosocial functioning.

Variables related to seizures and seizure knowledge may be associated with anxiety severity among PWE [5]. Smith, Baker, Dewey, Jacoby, and Chadwick [23] assessed 100 patients with medically refractory partial seizures. After controlling for psychosocial variables, they found that perceived seizure severity predicted anxiety. However, other seizure-related variables, such as time of onset of epilepsy, duration of epilepsy, and medications, were not associated with anxiety.

In summary, although few research studies have been conducted to assess the influence of social anxiety on the lives of PWE, anxiety in general has been found to be an important predictor of quality of life, seizure severity, stigma, and disclosure. It is unclear in the literature how similar psychosocial variables may be linked to and may be predictive of social anxiety among PWE. Thus, the aim of the present research was to examine such variables and how they are associated with social anxiety in a sample of PWE.

1.3. Present study

The current study was designed to determine which factors predict symptoms indicative of social anxiety among PWE and how social anxiety influences quality of life among PWE using online self-reports. In accordance with Baker et al. [13], it was hypothesized that lower levels of epilepsy knowledge would be associated with increased levels of social anxiety symptoms. Because of the limited literature on social anxiety among PWE, the remaining hypotheses were derived from the literature regarding anxiety and epilepsy and from the general social anxiety literature. If it is the case that social anxiety is related in a similar way as anxiety, it would be expected that social anxiety symptoms would be positively correlated with perceived seizure severity, felt stigma, and impact of epilepsy. Existing literature on general social anxiety indicates that these symptoms are positively associated with fear of negative evaluation and experiential avoidance [11,24]; therefore, it is expected that a similar pattern of results will be found among PWE. Conversely, elevated levels of social anxiety were predicted to be related to lower levels of epilepsy disclosure. Further, given the specific nature of symptoms associated with social anxiety (e.g., fear of negative evaluation and low self-disclosure), it was expected that social anxiety would account for unique variance in the prediction of both stigma and disclosure beyond anxiety, age, seizure frequency, depression, and impact of epilepsy. Finally, it was hypothesized that, in a situation where a seizure occurred in public and others were unaware of the epilepsy, participants would report greater judgment, anxiety, and rumination compared with those who were in a situation where others were aware of the epilepsy diagnosis.

2. Method

2.1. Participants

A sample of 101 PWE between the ages of 18 years old and 65 years old ($M = 37.51$, $SD = 12.93$) completed this internet-based study (see Table 1 for information on demographics). On average, participants had been living with their epilepsy for 17.74 years ($SD = 11.82$). Age at onset ranged from less than a year old to 53 years old ($M = 19.33$, $SD = 13.08$). Most of the participants (71.79%) were taking either one medication or two medications to control their seizures, while 17.50% were taking three to four medications, and 10.71% were not taking any medications.

2.2. Materials

2.2.1. Demographics

Basic demographic information was collected from the participants. They answered questions regarding their age, gender, ethnicity, education, and marital status. Participants also provided some information related to their seizures, such as the age at onset of their epilepsy, the kind of seizures they experienced, and the number of medications they were taking.