A qualitative examination and theoretical model of anxiety in adults with epilepsy

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ABSTRACT

Objective: There is an elevated prevalence of anxiety disorders among people with epilepsy, and the comorbidity of anxiety in epilepsy is associated with adverse medical and psychosocial outcomes. Despite its importance, little is known about what psychosocial or epilepsy factors may be associated with the development of anxiety. The aim of this qualitative study was to determine what factors may explain why some people with epilepsy develop anxiety disorders and others do not.
Methods: Adults with epilepsy were recruited from an outpatient epilepsy service. Semistructured interviews were conducted with 26 participants, 15 of whom reported clinically significant levels of anxiety. Grounded theory analysis was used to develop a theoretical model of anxiety development in the context of epilepsy.
Results: Qualitative analyses revealed a number of processes that appeared to account for the development of anxiety in the context of epilepsy. These included inflated estimates regarding epilepsy-specific risks and excessive attempts to avoid these risks. Such excessive avoidance often resulted in greater interference with participants' role functioning, thus risking ongoing quality of life. A number of premorbid and contextual factors also appear to be implicated in the development of anxiety.
Conclusion: This investigation provides a comprehensive account for the development of anxiety in epilepsy, which is consistent with existing theories of anxiety development and maintenance. Importantly, this model provides a foundation for future research and appropriate treatment strategies to address anxiety in people with epilepsy.

1. Introduction

It is widely agreed that the experience of living with epilepsy extends far beyond seizure management. People with epilepsy (PWE) confront a range of challenges in their day-to-day life, such as restricted independence, adverse effects of antiepileptic drugs (AEDs), stigma, and greater difficulty attaining educational and employment-related goals [1]. Poor adjustment to epilepsy results in increased psychological distress and poor quality of life [2,3]. Indeed, there is a high rate and elevated risk of psychiatric comorbidity among PWE [4,5], particularly anxiety and depressive disorders. In turn, the cooccurrence of depression and anxiety in PWE is associated with a range of adverse outcomes,

including poorer quality of life [6], increased healthcare utilization [7], poorer seizure control [8,9], and increased reporting of AED side effects [10].

Although much is understood about the factors that influence depression in epilepsy [11], less is known about anxiety [12]. In fact, in recent years, anxiety has been coined the "forgotten" or "neglected" psychiatric comorbidity in epilepsy, because of the limited research attention that it has received [12,13]. Despite its clinical and psychosocial importance in epilepsy, the current methods for detection and management of comorbid anxiety are insufficient.

Identifying anxiety in epilepsy is challenging because of the overlap between anxiety symptoms and clinical aspects of epilepsy itself (such as medication side effects and direct effects of seizures) [14]. For example, having shaky hands is both a common symptom of anxiety and a commonly reported AED side effect [15] while the sudden onset of fear is a feature of both panic attacks and some seizure types [14]. As such, little is known about which factors or processes account for why

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some PWE are more vulnerable to developing anxiety than others. Hence, the aim of the current study was to explore possible explanations for why some people experience anxiety problems and others do not and what processes play a role in the development and maintenance of anxiety in epilepsy. We utilized a qualitative, grounded theory methodology in order to develop an understanding of anxiety in epilepsy that was "grounded" in participants' lived experiences. This inductive methodology allowed us to build a theory of anxiety in epilepsy based on the data gathered and fill an important gap in our current understanding of anxiety in the context of epilepsy.

2. Methods

2.1. Participants and recruitment

Ethical approval was obtained from the Sydney Local Health District Human Research Ethics Committee. Twenty-six adult outpatients with epilepsy were recruited between February and July of 2017 (see Section 2.3 for an explanation regarding the number of participants recruited). Participants were English-speaking and required to be between 18 and 65 years old and to have a diagnosis of epilepsy (as diagnosed by their treating neurologist). Purposive sampling was employed to obtain a heterogeneous sample. This was to ensure that the data gathered represented diverse perspectives across different ages, genders, and epilepsy features. Such sampling also ensures that the perspectives gained are representative of the broader population of PWE. We also aimed to recruit 50% of participants with and 50% without significant levels of self-reported anxiety symptoms and ensured that demographic and epilepsy characteristics were well-represented across these two categories. Participants who attended neuropsychology consultations at the Royal Prince Alfred Hospital Comprehensive Epilepsy Service were provided with information about the study, a consent form, and a questionnaire. Participant details were either retrieved from a database (if they had consented to be contacted for research purposes) or they were provided with information about the study during their consultation. Of the 69 patients approached, 37 declined to participate (53%). Of the remaining 32, 6 were ineligible. Five of those excluded were females with self-reported anxiety above the moderate range and were thus excluded as the desired proportion of female to male participants with anxiety was ≤2:1 (broadly reflecting the distribution of anxiety in the general population; [16]). One participant with "mild" anxiety was excluded as a score in the mild range is not considered clinically significant (estimated around the 75th percentile; [17]), though it is still elevated above those reporting normal levels of anxiety. All remaining 26 participants completed the study.

2.2. Materials

Participants completed self-report questionnaires assessing demographic and epilepsy characteristics, including age, gender, marital status, educational attainment, employment status, epilepsy duration, seizure type and frequency, AED use (whether mono- or polytherapy), and self-reported perceived control over seizures. In addition, participants completed the 21-item Depression Anxiety and Stress Scales (DASS-21) [18]. The DASS-21 is a widely used self-report measure of psychological distress with robust psychometric properties [19]. It contains three subscales that provide scores related to the frequency of depression, anxiety, and stress symptoms over the past week. The anxiety subscale of the DASS-21 was used in order to assess the severity of participants' anxiety and assign attributes according to a large normative sample [18]. The scale has a minimum and maximum score of 0 and 42, respectively. A score of 0 to 7 on the anxiety subscale is classified as "normal", 8 to 9 is classified as "mild", 10 to 14 is classified as "moderate", 15 to 19 is classified as "severe", and a score equal to or greater than 20 is classified as "extremely severe".

For this study, individuals were considered nonanxious if they reported anxiety in the normal range and were considered anxious if they reported anxiety in the moderate, severe, or extremely severe ranges. Participants with anxiety in the "mild" range were excluded to ensure adequate distinction between groups within the sample, reflecting those reporting little to no anxiety symptoms ("normal" scores) and those reporting clinically significant anxiety symptoms (moderate and above).

Interviews were semistructured and contained questions exploring participants' epilepsy onset, adjustment to diagnosis, ongoing management of epilepsy, and influence of epilepsy on various aspects of life (such as relationships, work, education, self-esteem; see supplementary materials for interview schedule). Interview duration ranged between 31 and 79 min, with an average duration of 48 min (SD = 15.1). Twenty interviews were conducted via telephone, and six were conducted in person at the study site. Interviews were transcribed verbatim (with identifying information removed) and imported into NVivo (v11) for analysis [20].

2.3. Analysis

The interviews were analyzed using grounded theory methodology, which is a technique that allows researchers to develop a theoretical framework regarding a process of interest [21]. Grounded theory is considered inductive as it is a process of constructing a theory from the data itself. A distinctive feature of grounded theory is that data collection and analysis occur concurrently. Another important principle of grounded theory methodology is theoretical sampling, where researchers seek to gather additional data regarding a developing concept, so they may elaborate and/or refine their emerging theory [22].

After each interview was transcribed, open coding was conducted in a 'line by line' fashion to identify themes within the data. This involved assigning themes to words or groups of words in each line of text within interview transcripts. As data collection continued, these themes were compared against new data to determine how consistently they appeared in discussions of anxiety in epilepsy.

Next, axial coding was conducted. While open coding is thought to "fracture" or separate the data [22], axial coding involves integrating existing themes into conceptual relationships that are meaningful and coherent and that provide a theoretical explanation of the process of interest (here, anxiety in epilepsy). At this point, the existing themes and conceptual relationships were reviewed separately according to participant anxiety status (i.e., nonanxious or anxious). This allowed researchers to identify the themes and/or concepts that were unique to participants with or without anxiety.

Recruitment and analysis continued until theoretical saturation was achieved. Theoretical saturation occurs when no new themes emerged in open coding and the concepts developed in axial coding were also well-understood and sufficiently populated with qualitative data [22]. Two researchers coded the first four transcripts independently and then met to develop an agreed set of concepts. Following this, a single researcher analyzed the remaining interviews.

3. Results

Demographic and epilepsy features of the sample were well-represented between participants who reported DASS-A scores in the moderate to extremely severe range compared with those who reported anxiety in the normal range (i.e., those who were anxious compared with those who were nonanxious). See Tables 1 and 2 for sample characteristics and epilepsy characteristics of participants.

A number of themes emerged that covered participants' experiences with the process of diagnosis, ongoing management of epilepsy, interference of epilepsy in areas of life, and participants' psychological