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Metacognitive beliefs and illness perceptions are associated with emotional distress in people with epilepsy



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ABSTRACT

Purpose: Emotional distress is common in people with epilepsy (PWE) for which efficacious interventions are required. Developing evidence-based treatments should be based on testable models of the psychological mechanisms maintaining psychopathology. The Self-Regulatory Executive Function (S-REF) model proposes that maladaptive metacognitive beliefs and processes are central to the development and maintenance of emotional distress. Although preliminary support exists for the role of metacognitive beliefs in emotional distress in PWE, their role has yet to be tested when controlling for the contribution made by illness perceptions.

Methods: Four hundred and fifty-seven PWE completed an online survey, which assessed anxiety, depression, metacognitive beliefs, illness perceptions, general demographic factors, and epilepsy characteristics.

Results: Hierarchical regression analyses demonstrated that metacognitive beliefs and illness perceptions were both associated with anxiety and depression when controlling for the influence of demographic variables and epilepsy characteristics. However, metacognitive beliefs accounted for more variance in anxiety and depression than illness perceptions.

Conclusion: Metacognitive beliefs appear to make a greater contribution to anxiety and depression in PWE than illness perceptions. Prospective studies are now needed to establish the causal role of metacognitive beliefs in both the development and persistence of emotional distress.

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1. Introduction

Epilepsy is a common neurological condition affecting approximately 1% of adults [1]. In the UK, this translates to over 500,000 people with epilepsy (PWE) and over 3 million PWE in the USA. Anxiety and depression is very common in PWE. Estimates indicate that 30% of PWE meet diagnostic criteria for either an anxiety or depressive disorder, which often cooccurs [2–4]. The impact of anxiety and depression in PWE is substantial and can have a more negative influence on quality of life (QoL) than seizure frequency or severity [5] and the side effects of antiepileptic drugs (AEDs) [6]. It is imperative that clinical management of PWE is based on a comprehensive care plan, which includes the assessment and appropriate interventions for anxiety and depression [7, 8]. Several demographic variables are potential risk factors for anxiety and/or depression in PWE. These include being of younger age [9], being female [10], having lower socioeconomic status [11], not being in a relationship [12], not being in paid employment [13, 14], and having lower education attainment [15]. None of these variables are readily modifiable, and it may be that the identification and modification of core psychological mechanisms underpinning persistent emotional distress offers a more clinically useful direction [16, 17].

Unfortunately, the current understanding of the psychological mechanisms which underpin anxiety and depression in PWE is limited [18]. Theoretical advances may lead to increased treatment efficacy of psychological interventions [19]. Although a broad range of psychological factors are associated with increased prevalence rates of anxiety and/or depression, most reflect generic coping strategies and are not conceptualized within a well-specified theoretical framework. Arguably, the most widely evaluated theoretical framework for understanding emotional distress in physical health conditions is the common-sense model (CSM) of self-regulation, which consists of cognitive illness perceptions and emotional illness perceptions [20, 21]. It is important to note that the CSM was not specifically developed to account for emotional distress experienced by people with a physical illness. Instead, the CSM focuses on how illness perceptions about threats associated with illness led to coping strategies used by people with a physical health condition. However, several studies have investigated if illness perceptions are linked to the severity of anxiety and depression in PWE [22-25]. As an illustration, illness perceptions (e.g., "my epilepsy will last forever", "I have no control over my epilepsy") were better predictors of the severity of anxiety and depression than

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seizure-related variables [23]. Furthermore, a recent meta-analysis specified that illness perceptions have direct effects on distress and indirect effects on distress via coping behaviors [26]. Unfortunately, this model has not yet been translated into highly effective interventions for PWE experiencing anxiety and depression [27]. However, the CSM does represent an appropriate theory against which to judge alternative theoretical models hypothesized to account for emotional distress.

The Self-Regulatory Executive Function (S-REF) model [28, 29] offers an alternative conceptualization of anxiety and depression. According to this model metacognitive beliefs (i.e., beliefs about the control and execution of cognition) are fundamental determinants of emotional distress. The S-REF model contends that illness perceptions alone are insufficient to explain the development and maintenance of emotional distress. For example, negative illness perceptions are common in PWE, but the majority of PWE do not have clinical levels of anxiety or depression. The S-REF model instead proposes that it is how an individual responds to negative illness perceptions that lead to emotional distress. The response style is termed the cognitive attentional syndrome (CAS). The CAS consists of perseverative thinking (e.g., worry, rumination, overanalysing), threat monitoring (e.g., monitoring for negative thoughts or feelings), and counterproductive coping strategies (e.g., avoidance of social situations, persistent attempts to remove unwanted thoughts from consciousness).

The S-REF model specifies that it is a person's metacognitive beliefs, which determine whether they select and implemented the CAS in response to the experience of a negative illness perception. A broad range of metacognitive beliefs are specified in the S-REF model, but are often dichotomized into positive and negative metacognitive beliefs to help explain the basic tenets of the model. Positive metacognitive beliefs concern the benefits of engaging in each aspect of the CAS (e.g., "worrying helps me cope") and as such have an indirect effect on emotional distress. Negative metacognitive beliefs refer to the uncontrollability and danger of perseverative thinking (e.g., "I can't control my worry, rumination will make me lose control of my mind"), which maintain and increase perseveration and in turn increase levels of distress. Negative metacognitive beliefs have both a direct and indirect effect mediated by the CAS on emotional distress. In the S-REF model, negative illness perceptions can occur at any stage of perseveration (e.g., at the start of the worry process, during worry, or could be the consequence of a chain of worry).

In previous studies, metacognitive beliefs were associated with anxiety and depression in PWE independently of demographic and epilepsy related variables [18, 30]. However, the contribution of metacognitive beliefs to anxiety and depression in PWE has yet to be explored when controlling for the influence of illness perceptions. Exploring if metacognitive beliefs contribute to anxiety and depression when illness perceptions are accounted for offers a more rigorous test of the role of metacognitive beliefs in PWE. This current study therefore aimed to test the following hypotheses:

- Metacognitive beliefs and illness perceptions will be associated with anxiety and depression in PWE;
- Metacognitive beliefs will explain additional variance in emotional distress (anxiety and depression) after controlling for demographics, epilepsy characteristics, and negative illness perceptions in PWE.

2. Method

2.1. Participants and procedure

A cross-sectional online survey was used and approved by the University of Liverpool's Research Ethics Committee (Ref: RETH00103). Data were collected from 457 PWE; 35 participants logged on to the online survey but provided no data. To be eligible, participants had to be 18 years or older, diagnosed with epilepsy (of any type), and able to understand written English and provide informed consent. Participants were recruited by advertisements placed on the websites of epilepsy interest groups and organizations within England, Scotland, Wales, and the Republic of Ireland. Participants were informed that upon completion of the survey they could enter a prize draw.

2.2. Measures

2.2.1. Demographic and clinical characteristics

Participants provided demographic information (age, gender, educational level, relationship status, and employment status) and epilepsy characteristics (age at diagnosis, frequency of seizures over the past 12 months, AED monotherapy or polytherapy). In addition, participants' perceived experience of adverse effects due to their AEDs and their degree of worry about future seizures over the past 4 weeks were assessed by two items from the Quality of Life in Epilepsy (QoLIE-10 Version 2) [31].

2.2.2. Anxiety and depression

The Hospital Anxiety and Depression Scale (HADS) [32], a 14-item questionnaire, assessed the severity of anxiety and depression. Each item is scored on a 4-point scale, and scores for the anxiety subscale (HADS-A) and depression subscale (HADS-D) each range from 0 to 21. A subscale score of 11 or more, indicates "caseness", i.e., clinically significant levels of anxiety/depression. The HADS has satisfactory psychometric properties in PWE [33, 34], and both subscales had good internal consistency in the present study (HADS-Anxiety, $\alpha = 0.81$; HADS-Depression, $\alpha = 0.83$).

2.2.3. Metacognitive beliefs

The Metacognitions Questionnaire-30 (MCQ-30) [35] is a 30-item questionnaire that assesses five domains of metacognition: (i) 'Positive beliefs about worry' (POS) (e.g., "Worrying helps me cope"), (ii) 'Negative beliefs about uncontrollability and danger of worry' (NEG) (e.g., "My worrying is uncontrollable"), (iii) 'Cognitive confidence' (CC) (e.g., "My memory can mislead me at times"), (iv) 'Need to control thoughts' (NC) (e.g., "It is bad to think certain thoughts"), and (v) 'Cognitive self-consciousness' (CSC) (e.g., "I monitor my thoughts"). Each item is rated on the level of agreement with each statement presented on a fourpoint Likert scale (1–4). Subscale scores range from 6 to 24 with higher scores indicating greater conviction in metacognitive beliefs. The MCQ-30 has good psychometric properties in PWE [30]. In the present study, all subscales had at least acceptable internal consistency (POS $\alpha = 0.77$; NEG $\alpha = 0.85$; CC $\alpha = 0.91$; NC $\alpha = 0.77$; CSC $\alpha = 0.77$).

2.2.4. Illness perceptions

The Illness Perceptions Questionnaire-Revised (IPQ-R) [36] assesses seven illness perceptions (timeline acute/chronic, consequences, timeline cyclical, personal control, treatment control, illness coherence and emotional representations). In line with similar studies comparing the relative role of illness perceptions in the cognitive domain and metacognitive beliefs [37, 38], we did not use the emotional representations subscale. Furthermore, as recommended when using the IPQ-R, the specific condition being investigated should be reflected, therefore we changed the word "illness" to epilepsy.

Higher scores on the 'timeline (acute/chronic)', 'consequences', and 'timeline cyclical' subscales indicate greater conviction that the condition is chronic, that it has negative consequences on quality of life, and that it runs a cyclical course. Higher scores on the 'personal control', 'treatment control', and 'illness coherence' subscales indicate that a PWE more strongly believes that their epilepsy is controllable from both a personal and treatment perspective and that they consider themselves to have a good understanding of their condition.

The IPQ-R has good psychometric properties in PWE [36]. All IPQ-R subscales had at least good internal consistency in the present study (timeline acute/chronic $\alpha = 0.72$, consequences $\alpha = 0.84$, timeline cyclical $\alpha = 0.72$, personal control $\alpha = 0.79$, treatment control $\alpha = 0.75$, and illness coherence $\alpha = 0.91$).

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