



# Predicting wellbeing among people with epilepsy using illness cognitions



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## ABSTRACT

**Objective:** This study sought to examine the synergistic contribution of illness-related perceptions (stigma, severity, and threat) and illness behavior to wellbeing among people with epilepsy. Poorer wellbeing was expected among those who perceived greater stigma, illness severity, and threat and had more extreme illness behavior. **Methods:** Individuals with a diagnosis of epilepsy (N = 210), recruited through local and online support groups, completed a questionnaire comprising demographic and epilepsy-specific information, and validated measures of illness perceptions and behavior, epilepsy-related quality of life, and general psychological health.

**Results:** Bivariate associations among illness cognition, illness behavior, and wellbeing were all as expected. Structural equation modeling highlighted the strong, direct effect of illness threat on quality of life, with other contributions from perceived stigma and an abnormal illness behavior syndrome (i.e., maladaptive illness responses). Significant variance was accounted for in both quality of life (64%) and psychological health (34%). **Conclusion:** Preliminary evidence of the contributions of illness threat and maladaptive illness responses to wellbeing highlights the need for longitudinal research to examine the dynamic nature of such findings. Clinicians are encouraged to consider the potential value of screening for both illness threat and abnormal illness behavior to facilitate interventions.

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## 1. Introduction

Epilepsy impacts on daily living in terms of difficulties pursuing employment and education, attaining a driver's license, and greater risk of injury and death, with a mortality rate two to three times higher than the healthy population [1]. These challenges are often associated with poorer wellbeing such as increased depression, anxiety, and suicide [2,3]. Understanding the factors that enhance or impede wellbeing may result in improved interventions for chronic condition management [4]. Defining wellbeing in terms of epilepsy-specific quality of life and general psychological health, the current study sought to examine a range of illness cognitions hypothesized to translate to level of wellbeing.

As acknowledged by Hermann and Whitman [5], the psychosocial experience of epilepsy may be represented by the synergistic contributions of psychosocial variables such as illness cognitions and epilepsy-specific variables (e.g., illness duration). Perceived stigma is one such relevant cognition, with individuals often struggling to identify with the label of epilepsy [6]. The uncertainty of seizure occurrences and concerns about the judgments of others can contribute to a reticence to participate socially and increased isolation, for example. Stigma

may also combine with objective experiences (e.g., frequency of seizures, medication control, etc.) to inform a subjective interpretation of epilepsy severity [6]. While stigma and severity are likely to be predictive of wellbeing per se, their contribution is expected to be further understood by also considering two cognitive frameworks commonly used in the chronic illness context: self-regulatory model of illness and illness behavior.

### 1.1. Illness perceptions

The self-regulatory model (SRM) provides a social-cognitive context in which perceptions of illness may be examined [7,8], using the characteristics of 'identity' (the diagnosis and expected symptoms), 'timeline' (whether the illness is chronic, acute or cyclical), 'cause' (biological, emotional, environmental or psychological triggers), 'consequences' (expected effects including influence on life satisfaction), and 'cure/control' (the belief that the illness can be cured through treatment or controlled using self-management behaviors). A combined overall illness perception termed 'illness threat' is also noted to be associated with lower quality of life [7,9,10].

Although rarely applied to epilepsy, the role of illness perceptions in positive psychosocial outcomes has been demonstrated for other chronic illnesses including arthritis, cancer, diabetes, and myocardial infarction [9,11,12]. However, one available study reported that 'identity' was independently associated with anxiety, but not depression, among

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people with epilepsy [13]. Further, Jones and colleagues [14] compared the illness perceptions of those with well-controlled and poorly-controlled epilepsy and found that the latter believed their illness duration to be significantly longer than the former. A final relevant study identified illness perceptions to be significant predictors of depression and suicide risk among people with epilepsy, with ‘consequences’ as the strongest predictor [2].

### 1.2. Illness behavior

Also of potential importance to wellbeing is the underlying predisposition to respond to illness in a maladaptive way [15]. Illness behavior refers to *cognitive* and *affective* responses to somatic symptoms that affect the course of an illness and its treatment, which help clarify why some individuals react in extreme ways compared with others, despite similar symptomology. That is, while some people are inclined to deny illness, others become distressed by even minor bodily changes [15–17]. The psychiatric conception of abnormal illness behavior (AIB), pioneered by Pilowsky [18], quantifies constructs such as ‘hypochondriasis’, ‘denial’, ‘psychological vs. somatic’ (attribution of illness), ‘irritability’, ‘disease conviction’, and ‘affective disturbance’. However, illness behavior is now conceptualized as a general psychological continuum of potential illness responses with Prior and Bond [17,19] advocating three dimensions: ‘Affirmation of Illness’ (the extent to which the presence of illness is endorsed), ‘Concern for Health’ (health-related worry), and ‘General Affective State’ (emotional distress, regardless of the presence of illness). Therefore, extreme responses are described as the general tendency to become preoccupied with illness, and to display high levels of illness-related anxiety and emotional distress.

As with illness perceptions, there is only limited research into the illness behaviors of people with epilepsy. However, Stone et al. [20] identified that participants with recent-onset psychogenic nonepileptic seizures considered psychological factors to contribute less to their disease than those with recent-onset epilepsy. Those with psychogenic nonepileptic seizures also reported greater levels of denial, attributing all problems to their illness. Further, Lykouras and colleagues [21] examined whether psychiatric morbidity and illness behavior were linked among neurological inpatients (19% epilepsy). ‘Irritability’ was higher among those with a psychiatric diagnosis compared to those without. Similar, but non-significant, trends were found for ‘hypochondriasis’, ‘disease conviction’, and ‘affective disturbance’, with lower scores also noted for ‘denial’. The implications for epilepsy specifically were not addressed.

### 1.3. Summary

Perceptions of stigma and severity represent central cognitions likely to be associated with wellbeing. Illness perceptions and illness behavior offer additional conceptual frameworks to further examine wellbeing. Illness perceptions are context-specific and primarily seek to understand responses to illnesses where pathology is evident. Conversely, illness behavior reflects a general approach to a variety of illness circumstances and was originally conceptualized to understand dysfunctional presentations disproportionate to apparent pathology. However, both comprise cognitive and affective interpretations of the illness experience.

The current goals were to determine associations between a range of illness-relevant cognitions and wellbeing. It was hypothesized that poorer wellbeing (epilepsy-specific quality of life and general psychological health) would be reported by those expressing greater stigma, severity, and illness threat, and more extreme (higher) illness behavior scores. The final goal was to further characterize the identified associations by testing a model of the potential pathways between cognitions and wellbeing.

## 2. Material and methods

### 2.1. Participants and procedure

Approval for the study was obtained from the authors’ local research ethics committee. Participation was voluntary and there was no extrinsic incentive to participate. Data were obtained from 210 people with a diagnosis of epilepsy who were sourced from both local and online support groups. Potential participants were at least 18 years of age and able to understand verbal and written English instructions, and to provide informed consent. They were also required to have an epilepsy diagnosis of at least 6 months, to allow time for initial psychological assimilation of the requirements of the condition [22].

The study was promoted via email and social media platforms, which provided both an online link and instructions on how to receive a paper copy of the questionnaire. The first author also attended local support groups to distribute information to willing attendees. In all cases, participants were supplied with written details (e.g., the study aims, the right to withdraw at any time or to refuse to answer individual questions, the assurance of confidentiality and anonymity). The questionnaire was completed in participants’ own time either online or by returning a paper copy in the reply-paid envelope provided.

### 2.2. Questionnaire

Standard sociodemographic characteristics (e.g., age, sex, education, marital status) and epilepsy-specific details (e.g., age at diagnosis, perceived severity ranging from 1 ‘not severe at all’ to 7 ‘extremely severe’, perception of stigma ranging from 1 ‘no stigma’ to 7 ‘extreme stigma’) were sought, along with responses to the following validated scales.

#### 2.2.1. Illness perceptions

The Brief Illness Perception Questionnaire [23] allows a rapid assessment of cognitive and emotional illness representations in accord with the SRM [8]. Cognitive representations comprise consequences, timeline, personal control, treatment control, and identity and include items such as ‘How long do you think your illness will continue?’ (timeline). A single item taps emotional representations (‘How much does your illness affect you emotionally?’), while illness coherence reflects a combination of cognitive and emotional representations (e.g., ‘How well do you feel you understand your illness?’).

In accord with recommendations [10,12], the wording of items was changed from ‘your illness’ to ‘your epilepsy’ to increase the relevance to participants (e.g., ‘How long do you think your epilepsy will last?’). Responses are provided on 11-point Likert scales with the specific end-points altered to match each representation (e.g., 0 = ‘not concerned at all’ to 10 = ‘extremely concerned’). A global score (illness threat) is computed by summing responses to the eight items (range 0–80) with higher scores indicating that epilepsy is perceived as more threatening. Internal consistency ( $\alpha$ ) was .77 for the current sample.

#### 2.2.2. Illness behavior

The 31-item Illness Behavior Questionnaire (IBQ-31) is an abridged version of the original IBQ which quantifies three constructs [19,24]. Affirmation of Illness (12 items;  $\alpha = 0.77$ ) measures the extent to which individuals believe they have an illness (e.g., ‘Do you think there is something wrong with your body?’). Concern for Health (8 items;  $\alpha = 0.82$ ) focuses on health-related worry with items such as ‘Do you worry a lot about your health?’ General Affective State (11 items;  $\alpha = 0.82$ ) includes questions pertaining to emotional distress, regardless of illness (e.g., ‘Except for epilepsy, do you have any problems in your life?’). Each question requires a ‘yes’ or ‘no’ response. Scale scores are calculated by allocating a point for each endorsed item that reflects AIB. Higher scores for each scale indicate more maladaptive responses. The reliability and

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