



# Deconstructing stigma in psychogenic nonepileptic seizures: An exploratory study

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## ABSTRACT

Psychogenic nonepileptic seizures (PNES) are classified as a mental disorder, the manifestations of which superficially resemble epileptic seizures.

There is a notable lack of in-depth qualitative or quantitative studies investigating the stigma attached to PNES. The current study is an exploratory analysis into the nature of perceived stigma in those with PNES when compared with individuals with epilepsy. Individuals with epilepsy ( $n = 78$ ) and PNES ( $n = 47$ ) were recruited from a United Kingdom hospital or membership-led organizations for individuals living with seizures. Participants were asked to complete a series of questionnaires investigating health-related quality-of-life components (NEWQOL-6D), anxiety (GAD-7), depression (NDDI-E), seizure frequency and severity (LSSS-3), and illness perception (B-IPQ). Perceived stigma was measured using one question taken from the NEWQOL-6D. Individuals with PNES reported a greater level of perceived stigma than those with epilepsy ( $p = 0.04$ ). Our results indicate that the risk of experiencing perceived stigma in PNES was 42% higher than the risk in epilepsy. In epilepsy, but not PNES, perceived stigma was significantly associated with seizure frequency, anxiety, depression, and many of the sequelae of the condition. In both conditions, self-control was associated with stigma ( $\rho \geq 0.34$ ,  $p \leq 0.01$ ). This study was exploratory, and so definitive conclusions cannot be made; however, our findings suggest that the majority (87.2%) of individuals with PNES reported experiencing some degree of perceived stigma, the risk of which is greater than that in epilepsy. Further research is needed into the prevalence, nature, and consequences of stigma in PNES.

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## 1. Introduction

Stigma refers to the devaluation or discrediting of an individual because that person is in possession of an attribute or characteristic that distinguishes that person from others [1]. The tendency to stigmatize people because they have an illness or disability is well known, with some medical conditions more likely to be associated with stigma than others, for example, mental health [2] and visible skin disorders [3].

The association between stigma and epilepsy has been documented through much of human history and across many cultures. Seizures have been considered (and still are in many parts of the world) contagious, a sign of spirit possession, or a bad omen [4]. Despite great advances in the scientific understanding of epilepsy and significant investment in public educational campaigns, poor attitudes toward epilepsy and understanding of the disorder still persist [5–8].

Stigma represents a disquieting obstacle for many individuals living with epilepsy. Indeed, stigma has been shown to have far- and wide-ranging consequences on many aspects of daily life; it has been well documented across different cultures that epilepsy-related stigma is a strong correlate and an important predictor of health-related quality of life [9–12].

Stigma can operate at different levels. Internalized stigma is where individuals discriminate against themselves because they come to believe the negative stereotypes that are associated with their condition. In epilepsy, internalized stigma has been associated with increased levels of fear, anxiety and seizure severity, and a greater need for information and support relating to epilepsy [13]. Externalized stigma refers to the experience of being discriminated against by others. In 2000, a study investigating over 5000 adults living with epilepsy in European countries reported that 51% of individuals had previously experienced feelings of stigma [8]. What is more, qualitative studies exploring the phenomenology of epilepsy have helped to expose the detrimental impact that actual, perceived, and feared stigmatization can have on individuals, with many reporting that they have been the victim of negative stereotypes, discriminative behavior, and prejudicial acts [14].

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Psychogenic nonepileptic seizures (PNES) are characterized by episodes of impaired self-control associated with a range of motor, sensory, and mental symptoms. Although the visible manifestations of PNES superficially resemble those of epilepsy, they are not caused by epileptic discharges. Instead, PNES are classified as a mental disorder in the medical nosologies [15,16]. Most PNES are best understood as a dissociative response to distressing stimuli [17]. Psychogenic nonepileptic seizures are not rare as approximately one in five patients that present to seizure clinics is diagnosed with the condition [18]. In clinical practice, PNES can prove difficult to distinguish from epilepsy, and many patients with PNES are misdiagnosed and inappropriately treated with antiepileptic medication for many years [19].

Given that PNES are a mental disorder manifesting with seizures superficially resembling that of epilepsy, it is not surprising that the limited existing literature on this topic suggests that individuals with PNES experience stigma [20–22]. Indeed, recent insights from a qualitative study examining written accounts of living with PNES suggest that many individuals experience distressing levels of stigma attributable to their condition [23]. However, to date, studies that have reported PNES-related stigma only do so indirectly, and stigma has not been the study objective in any published works relating to PNES. There is a notable lack of in-depth qualitative or quantitative investigations intended specifically to explore the stigma attached to PNES. This means that very little is actually known about the nature, prevalence, and perception of stigma associated with this condition. The relative dearth of research is particularly striking when the literature on PNES-related stigma is compared with that on epilepsy or mental health disorders — both found more commonly in individuals with PNES than expected in the general population [24,25].

The purpose of this exploratory study was to investigate the prevalence and risk of perceived stigma in PNES by comparing the responses of individuals with the condition with those with epilepsy. In an attempt to deconstruct the nature of stigma in PNES, our second aim was to explore the relationship between perceived stigma and a series of demographic, clinical, and psychological factors as a function of epilepsy or PNES.

Exploratory research designs are used to investigate an area of research where there is a lack of past studies. As such, our purpose was not to arrive at definitive conclusions but, rather, to raise an important issue, to become acquainted with this topic, and to formulate questions for future investigations.

## 2. Methods

This dataset represents a part of the baseline measures for a prospective study investigating a writing intervention for individuals with seizure disorders. Different aspects of this dataset have been analyzed and reported previously [26].

### 2.1. Participants

Individuals were recruited from outpatient neurology clinics at the Royal Hallamshire Hospital, Sheffield, UK, and from membership-led organizations for individuals who experience seizures (see Acknowledgment for the list of organizations). Recruitment took place between October 2015 and November 2016. The North of Scotland Research Ethics Committee granted ethical approval for this study.

The inclusion criteria for the current study stipulated that participants must have a diagnosis of epilepsy or PNES (individuals thought to have mixed seizure disorders were excluded from the study), be over the age of 18 years old, be living in a Western culture, have experienced a seizure within the last 12 months, and be able to provide informed consent and complete a series of demographic and clinical questionnaires without help. The diagnoses of individuals were self-declared. The diagnoses of those recruited from neurology clinics were confirmed by reviewing their medical records. When possible,

confirmation of the self-reported diagnoses of individuals recruited through membership-led organizations was sought from their General Practitioner.

### 2.2. Data collection

Individuals recruited from outpatient neurology clinics were sent a participant information sheet at least 48 h before their appointment with a Consultant Neurologist. On the day of their appointment, the participant was approached in the waiting room by G.R. and invited to take part in the study. Those who agreed to take part were then asked to complete a set of self-report measures. Participants recruited from membership-led organizations replied to an advert for a study of a writing intervention designed to help patients with seizure disorders. The individual then contacted G.R. who gained written informed consent and provided access to an online form where participants could complete the self-report measures.

### 2.3. Self-report measures

#### 2.3.1. Perceived stigma and health-related quality-of-life components

A question taken from the NEWQOL-6D was used to investigate perceived stigma. Individuals were asked in the context of their seizures: *How much do you feel people treat you as an inferior person?* Participants responded using a four-point Likert scale (*I do not feel that people treat me like an inferior person, I feel that some people maybe treat me like an inferior person, I feel that some people probably treat me like an inferior person, or I feel that people definitely treat me like an inferior person*). This question was originally derived from the Stigma of Epilepsy Scale [27]. The NEWQOL-6D also measured participants' memory and concentration problems, perceived control over events, and how worried they are about their next seizure. A lower score represents a better outcome [28].

#### 2.3.2. Demographic questionnaire

This recorded individual's age, gender, address, and years of education. Participants were also asked how long they have experienced their seizure disorder.

#### 2.3.3. Anxiety

Anxiety symptoms were assessed with the seven-item Generalized Anxiety Disorder (GAD-7) questionnaire. Individuals were asked to report on a four-item Likert scale (Not at all, Several days, More than half the days, Nearly every day) how often they have been bothered by anxiety-related problems over the past 2 weeks. Scores between 5 and 9 suggest mild, 10–14 moderate, and > 15 severe anxiety [29].

#### 2.3.4. Depression

Depressive symptoms were measured with the six-item Neurological Disorders Depression Inventory for Epilepsy (NDDI-E). Participants were asked to report on a four-item Likert scale (Always or Often, Sometimes, Rarely, Never) how best depression-related statements describe them over the last 2 weeks. Scoring above the cutoff of 15 suggests a major depressive episode [30].

#### 2.3.5. Seizure frequency and severity

The Liverpool Seizure Severity Scale (LSSS-3) is a twelve-item self-report questionnaire asking individuals about their experiences of seizure frequency in the past year and the severity of their seizures in the last 4 weeks. It is scored from 0 to 100 with higher scores reflecting greater seizure severity [31].

#### 2.3.6. Illness perception

Illness perception was measured using the eight-item Brief-Illness Perception Questionnaire. This assesses individuals' perception about consequences, time-line, personal control, treatment control, symptoms,

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