



Written accounts of living with psychogenic nonepileptic seizures: A thematic analysis



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ABSTRACT

Purpose: Qualitative studies examining lived experiences of psychogenic nonepileptic seizures (PNES) have predominantly relied on datasets collected using clinical or research interviews. This study pursued a different approach by investigating individuals' written accounts of their condition.

Methods: Participants (n = 19) were recruited from membership-led organisations for individuals living with seizures and from a United Kingdom hospital. Participants were instructed to produce four pieces of writing: 1) about their thoughts and feelings about their condition; 2) a letter to their condition; 3) a letter to their younger self; and 4) about a personal value. All writings were analysed using thematic analysis.

Results: Six main-themes emerged from the data. Theme 1: 'living with PNES' demonstrated that all participants presented the condition as having a debilitating effect. Theme 2: 'Emotions' revealed that individuals were struggling with anxiety, low mood and self-worth. Theme 3: 'Seizure symptoms' showed variability was a prominent feature in the description of ictal events. Theme 4: 'Treatment and outcomes' demonstrated that individual's perception of diagnosis and therapy differed greatly. Theme 5: 'Causation and development' revealed that the majority of participants spontaneously reported experiencing a traumatic event in the past. Theme 6: 'Lack of understanding' by themselves, the public and healthcare professionals appeared to pose considerable challenges to participants.

Conclusions: Qualitative research has an important role to play for improving our understanding of PNES. The findings contribute to the literature by highlighting the nature of stigma that people with PNES experience, and also their proneness to demonstrate problems with self-worth.

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1. Introduction

Psychogenic nonepileptic seizures (PNES) are one of the most important differential diagnoses of epilepsy. PNES superficially resemble epileptic seizures, but are not associated with epileptiform activity. Instead, PNES are considered to have a psychological basis and can be best understood as a dissociative response to distressing stimuli [1,2]. Approximately one in five patients referred to epilepsy clinics will have PNES [3,4].

Most research investigating the psychological aspects of PNES has utilised quantitative methodologies [5]. These studies have

demonstrated that PNES are intra- and inter-individually heterogeneous in terms of clinical manifestations [6,7], aetiology [8], comorbidities [1], socioeconomic and demographic variables [4], personalities [9], psychological and emotional profiles [10], coping styles [11,12], response to treatments [13,14], and prognosis [15].

Whilst quantitative studies have provided many insights into the characteristics of PNES, they are at risk of oversimplifying the complexities and idiosyncrasies of how the condition impacts individual patients. For example, participants typically have to respond to questions using pre-defined categorical answers and are unable to clarify or communicate the finer subtleties and variations of their experiences. Qualitative methodologies on the other hand, allow researchers to ask more general and open-ended questions. These approaches encourage individuals to tell their story, in their own words, which means that responses are more likely to reflect the challenges and concerns they experience as most important. Whilst this means that the data collected can be

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more difficult and time consuming to interpret or categorise, it is fine-grained and rich in detail.

How we experience and narrate an event is a highly personal and complex process, which is affected by a range of influences including cultural and psychosocial factors [16]. It follows that the use of different methodologies to analyse and collect data to investigate subjective accounts are likely to produce the best possible insights into a problem. However, a recent systematic synthesis of the qualitative literature examining the phenomenology of PNES reported that, whilst a range of different qualitative analytic approaches have been used, studies to date have predominately relied on datasets collected using clinical or research interviews [5].

The current study pursues a different approach of data collection and aims to deepen our understanding of living with PNES through the thematic analysis of people's writing about their condition. Writing has been considered an individual act allowing for private consideration, exploration and expression of thoughts and feelings [17]. Compared to the more immediate nature of spoken responses, writing gives individuals more opportunity for reflection and control over their account. The same research design and methodology has been used to investigate the subjective experience of living with epilepsy. This produced revealing insights into how people with epilepsy manage the condition and highlighted some important considerations for clinical practice [18].

2. Methods

2.1. Participants

Participants were primarily recruited through membership-led organisations for individuals experiencing seizures (see acknowledgements for the list of organisations). Participants recruited from such organisations self-declared that they had received a diagnosis of PNES and that they did not experience epileptic seizures as well. Participants were also approached consecutively and recruited from outpatient neurology clinics at the Royal Hallamshire Hospital, Sheffield (United Kingdom, UK). Recruitment took place between October 2015 and November 2016. The North of Scotland Research Ethics Committee granted ethical approval for this study (15/NS/0078). Participants were included if they were over the age of 18 years, had a diagnosis of PNES (participants with comorbid epilepsy and PNES (either self-declared or proven) were excluded), and were able to complete a demographic and clinical questionnaire without help. The diagnosis of individuals recruited at the Royal Hallamshire Hospital was confirmed by review of their hospital records. When possible, confirmation of the self-reported diagnoses of participants recruited through membership-led organisations was sought from their General Practitioner.

2.2. Data collection

This dataset was collected in the context of a randomised control trial investigating the effects of an expressive writing intervention for individuals with seizure disorders. The current study is based exclusively on data from participants with PNES allocated to the *intervention* group. A total of 19 individuals were included, which is the number of participants recruited to the intervention at the time that the current study was undertaken. Participants recruited from membership-led organisations replied to an advert for a study of a writing intervention designed to help individuals with seizure disorders. Potential participants then contacted G.R. who gained written informed consent and provided access to an online form allowing participants to complete the self-

report measures. Participants 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, individuals were approached and invited to take part in the study. Those who gave written consent were asked to complete a set of self-report measures.

All participants were then given four writing booklets. Each booklet contained writing instructions, space for writing (four A4 sheets of lined paper) and a link to a website for those participants preferring typing to handwriting. Participants were asked to produce four pieces of writing: 1) their very deepest thoughts and feelings about their condition [19]; 2) a letter to their condition [17]; 3) a letter to their younger self [20]; and 4) about a personal value and why it is important [21]. The topics had been set based on previous studies of writing therapies in other patient and non-clinical groups. Participants were asked to write for at least 20 min per question, at home and in private.

2.3. Self-report measures

Participants completed a demographic questionnaire that recorded their age, gender, employment status and years of education. Participants were also asked how long they had experienced PNES and the date of their last seizure. To investigate the effectiveness of the writing intervention, outcome measures were taken at baseline, one- and three-month follow-up. For this purpose, participants' health-related quality of life (HRQoL) was investigated using the NEWQOL-6D [22]. This is a six-item HRQoL measure specifically developed for individuals with seizures. A higher score represents a better HRQoL (0.96–0.34). The Generalised Anxiety Disorder (GAD-7) was used to measure anxiety [23]. This is a seven-item scale used as a screening tool and severity measure of mild (score of 5–9), moderate (10–14) and severe anxiety (>15). The six-item Neurological Disorders Depression Inventory for Epilepsy (NDDI-E) was used to screen for likely major depression [24]. Scoring above 15 suggests a current major depressive episode. Seizure frequency and severity were investigated using the Liverpool Seizure Severity Scale questionnaire (LSSS-3) [25]. This is scored from 0 to 100 with a higher score representing greater seizure severity. The baseline scores have been reported in the current study to provide some information about the group of individuals sampled here – this allows readers to relate our findings to the patient populations they treat or study.

2.4. Data-analysis

The qualitative approach was guided by the methodology of thematic analysis [26]. This method was based on a mixed inductive (themes were grounded in the data) and theoretical approach (themes were influenced by the existing literature, primarily from the themes identified in a systematic synthesis of qualitative research into PNES [5]). Participants' answers to each of the four questions were read separately, but as individuals expanded on experiences mentioned in their initial writings in later sessions it was decided that their written responses to all four topic prompts would be considered together in the analysis. The data was analysed in six steps (Table 1). In the results section, the main themes are presented in the order in which participants often structured their written accounts. Participants quotes are represented by "".

Measures were taken to ensure the trustworthiness of our findings, including expert checking and working reflexively [27]. Participants were informed that they should write for themselves as they would not be contacted about what they wrote. Whilst this meant that individuals may have felt that they could have been

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