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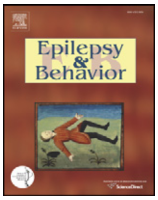

Understanding the perceived treatment needs of patients with psychogenic nonepileptic seizures

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ABSTRACT

Psychological therapy is generally considered the treatment of choice for psychogenic nonepileptic seizures (PNES), but there is a paucity of research on patients' attitudes towards psychological referral. We conducted semistructured interviews with twelve patients with PNES awaiting psychological treatment in order to understand their perceived treatment needs. Data were analyzed inductively according to the principles of thematic analysis. The results indicated that our patients had clear ideas about their treatment needs and a desire to recover by 'returning to normality'. Many participants felt 'caught in limbo' following their PNES diagnosis, however, because of uncertainties about their condition and a lack of support from professionals. This linked with participants feeling unsure whether psychological treatment would meet their needs; there was also apprehension for some participants about the potential negative consequences of therapy. The clinical implications of these findings are discussed, and recommendations for future research are made.

1. Introduction

Psychogenic nonepileptic seizures (PNES) are episodes of altered movement, emotion, sensation, or experience, which are superficially similar to epileptic seizures but without the associated electrical brain activity [1]. PNES patients with PNESs represent about one in five new patients seen in specialist epilepsy services [2]. Obtaining an accurate diagnosis can take several years [3,4] and can involve patients undergoing unnecessary medical investigations and receiving treatment that may have iatrogenic side effects [5]. Delays also result in patients not receiving timely and appropriate psychological treatment [6,7].

The etiology of PNES appears heterogeneous and is generally conceptualized through multifactorial models that include biological and psychosocial contributions [8–11], although a widely accepted theoretical model of PNES is lacking [10,12]. Influential factors in the development and maintenance of PNES include the following: trauma [13–15], family dysfunction [9,16,17], personality factors [8,18,19], neurological abnormalities [20,21], stressful life events [9,22,23], psychopathology [24–26], and avoidant coping styles [27,28]. There is limited knowledge about the most effective ways of managing and treating PNES [29]. The main approaches include diagnostic communication strategies [30,31], psychoeducational interventions [32,33], pharmacological interventions [34], and various psychological therapies [35,36]. Reviews of psychological treatment for PNESs have found no evidence to support a particular approach [37,38]. Nevertheless, psychological intervention is considered the treatment of choice by professionals [39,40].

Gaining the views of those who use services (service users) is central to developing 'needs-led' and patient-centered services [41]. Benefits of service user involvement include developing effective care partnerships, increased understanding of the illness experience PNES and patient empowerment [42]. Despite the evident importance of service user research, only a small number of studies have explored the perspectives of patients with PNES. Research has typically focused on patients' experience of their diagnosis. Studies report that most patients agree with their diagnosis [32,43–45], although doubts are also commonplace. Doubts often relate to the perceived relevance of the diagnosis [44,46] and the psychological nature of the condition [32]. Some patients meet their diagnosis with positive feelings [30,43,46–49], while others experience distressing emotional reactions [30,43,46–49]. Further common themes include perceived loss of control [30,44,46], difficulties in understanding the condition [30,32,44,46,47,49], impairments due to the condition [32,46,49], and feelings of isolation and loneliness [44,46,49,50]. Patients with PNES also report feeling uncertain about recovery, and their optimism for the future varies widely [44,48].

With regard to treatment needs, patients report needing more understanding and information about PNES [32,46]. Those patients who identify with a psychological understanding of their condition have a better appreciation of the rationale for therapy [46,50]. Patients with PNES vary in their experience of therapy, with some seeing benefits in learning relaxation techniques and having the time to discuss problems,

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and others perceiving therapy to be a 'failure' due to brief involvement and difficult therapeutic relationships [32,49].

To date, there have been no in-depth studies investigating patients' perceptions of treatment for PNESs. The current study aims to fill this gap by capturing patients' perspectives on treatment needs and expectancies for forthcoming psychological treatment to inform the future management and treatment of this neglected patient group. Patients' expectancies of therapy are an important nonspecific therapeutic factor [51,52]. Research indicates that having positive expectations for the outcome of therapy results in better therapeutic alliances and outcomes [51]. Understanding therapy expectations may be particularly important for patients with PNESs given that a quarter of patients with functional neurological symptoms do not attend their first appointment for psychological therapy [53].

2. Methods

A qualitative method using semistructured interviews was chosen to gain an in-depth and contextual understanding of the perspectives of patients with PNESs regarding psychological treatment. The data collection and analysis followed an inductive and interpretive approach informed by principles of thematic analysis [54,55]. The interviewer was a female in her late twenties undergoing doctoral training in clinical psychology. She had limited clinical experience with the patient group but was experienced in neuropsychology. Because of her background and training, she held a strong 'insider's perspective'. The wider research team consisted of two clinical psychologists and a neurologist who were experienced clinically and academically with PNESs. Supervision was also provided by a clinical psychologist experienced in qualitative methods.

2.1. Recruitment and sampling

Participants were recruited from a PNES treatment waiting list, from a National Health Service (NHS) Department of Clinical Neuropsychology, between August 2011 and January 2012. Ethical approval was gained from the National Research Ethics Service Committee North West (Reference: 11/NW/0376). Patients were typically placed on the waiting list by their neurologist following their diagnosis of PNESs. Patients were informed of the referral, although standard practice was not to provide information on the likely length and type of therapy or give written information about the psychology service. Patients were eligible to take part if they were aged ≥16 years and had received a diagnosis of PNESs, confirmed by a neurologist in the preceding twelve months. Basis for exclusion included the following: comorbid epilepsy, severe communication difficulties, or severe learning disability. Patients who had received psychological therapy for PNESs in the preceding 12 months were also excluded given the focus of the research. However, patients with past or current psychological involvement relating to other difficulties were not excluded to ensure a representative sample.

Potential participants were identified from the waiting list for psychological treatment by an assistant psychologist. Those who met the selection criteria were sent an information sheet and a postal form to declare their interest in participating. Potential participants were also able to contact the lead researcher (GF) to opt in directly. Upon confirmation of interest in the study, meetings were arranged with potential participants, and a demographics questionnaire was sent to be completed prior to meeting. Participants were compensated £10 to cover time and costs.

2.2. Data collection

2.2.1. Interview procedures

Interviews were arranged either at the neuropsychology department or at participants' homes. Written informed consent was taken by the lead researcher. All interviews were conducted individually to ensure confidentiality and encourage openness. Interviews were digitally recorded and transcribed verbatim.

Interviews were semistructured and followed a typical format for in-depth interviews [56], having a small number of open-ended questions followed by further prompts. The interview guide was initially developed through discussion between the lead researcher, an experienced PNES researcher and clinician (RB), and an experienced qualitative researcher (JF). A consensus on the guide was gained from researchers and clinicians in the NEST research group [57]. The guide covered four areas: understanding of the condition, current treatment needs, past treatment experiences, and expectations of psychological therapy. The guide was reviewed by the research team and collaborators following the second interview, and adaptations were subsequently made. Iterative development of the guide continued throughout subsequent interviews.

2.2.2. Questionnaires

Participants completed a demographics questionnaire and two further questionnaires assessing symptoms of psychopathology and trauma. The questionnaires help to describe the sample and provide context to interview data.

2.2.2.1. Brief Symptom Inventory [58]. The Brief Symptom Inventory (BSI) is a 53-item questionnaire with good psychometric qualities [58,59] that assesses symptoms of psychological distress. The total of all responses results in a Global Severity Index (GSI) score that can be interpreted in terms of likely 'caseness'.

2.2.2.2. Trauma Symptom Checklist [60]. The Trauma Symptom Checklist (TSC) is a 40-item questionnaire that assesses symptoms of trauma. It has proven reliability and predictive validity [60,61]. This questionnaire was chosen as a proxy measure of trauma.

2.3. Analysis

The analysis was informed by guidelines set out by Braun and Clarke [55] for inductive or 'data-driven' thematic analysis. Initial stages of analysis involved the researcher 'immersing herself' in the data, followed by open coding of the data using a process of 'constant comparison' [62]. Memos captured developing ideas about the data. In line with the inductive nature of the research, analysis was carried out in parallel with ongoing data collection.

The data were organized into themes by sorting codes according to relationships between them. Initial thematic maps were developed to test out potential thematic structures, and these were revised through revisiting the data and refinement of codes. This iterative process continued until a final set of themes was identified, which provided a cohesive representation of the data.

The research process was informed by the guidelines for conducting qualitative research [63,64]. To ensure quality, a reflective diary was kept, credibility checks were performed, and attention was paid to instances of disconfirming data. During analysis, themes were shared with the members of the research team (JF and RB) who assisted in their refinement. To demonstrate the validity of the data, illustrative quotes have been selected to support the results.

3. Results

In total, 40 potential participants were contacted and 17 expressions of interest were received. Three people did not meet the inclusion criteria, one person withdrew their consent prior to participating, and another person completed an interview that was subsequently excluded as it emerged that this participant had commenced therapy for PNES at the time of interview. Twelve interviews were included in total. Medical records confirmed that all participants had a diagnosis of PNESs made by a specialist neurologist. The twelve interviews lasted between