



What is it like to receive a diagnosis of nonepileptic seizures?

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ABSTRACT

The aim of this qualitative study was to provide insight into the experience of receiving the diagnosis of nonepileptic seizures (NES) from the patient's perspective. Semistructured interviews were conducted with eight patients who had received the diagnosis of NES over the preceding 6 months. All participants were on a waiting list for psychological treatment. Verbatim records of the interviews were analyzed using interpretative phenomenological analysis (IPA). Six main themes emerged from the data ("the experience of living with nonepileptic seizures", "label and understanding", "being left in limbo land", "doubt and certainty", "feeling like a human being again", and "emotional impact of diagnosis"). An ability to integrate the diagnosis into a personal narrative was key to participants' acceptance of the diagnosis. The communication of the diagnosis left some participants feeling distressed. The results suggest that patients need more time and resources to understand the diagnosis and more support after they have received it.

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1. Introduction

Nonepileptic seizures (NES) are episodes of altered movement, sensation, or experience that resemble those caused by epilepsy but are not due to abnormal electrical activity in the brain [1]. NES are episodes of paroxysmal impairment of self-control associated with a range of motor, sensory, and mental manifestations, which represent an experiential or behavioral response to emotional or social distress [2]. NES are one of the most common diagnoses in a seizure clinic. One study, which reportedly captured all patients with a blackout first presenting to a neurologist, emergency room, or primary care physician, judged that 57.4% had epilepsy, 22.3% had fainted, and 18.0% had NES [3]. NES represent a serious medical problem: patients are at risk of iatrogenic injury and death from inappropriate treatment with antiepileptic drugs [4,5], and often have disabling psychopathology [6]. Although the etiology and nosology of the condition remain controversial [7], most experts consider psychotherapy the treatment of choice [8,9].

The uncertainties around NES are reflected by the large number of different labels used for the condition [10] and by the lack of agreement on how the diagnosis should be communicated [11,12]. However, it is recognized that the communication of the diagnosis of NES represents a significant challenge: the majority of patients have had a diagnosis of epilepsy for several years when

they learn that this diagnosis is inaccurate [13], most have been treated inappropriately with antiepileptic drugs, and many have been admitted to hospital with apparent status epilepticus [14]. As with other "medically unexplained" illnesses, a perception exists in some parts of the medical community that there is a marked incongruence between doctor and patient beliefs about the cause of symptoms: that doctors consider them to be a manifestation of distress or mental illness, whereas patients believe them to be almost exclusively physical ([e.g., 15]). Some studies suggest that patients may acknowledge psychological or social stressors but not consider these relevant to their seizure disorder [16]. An alternative view is that this apparent difference is a function of the language used in the consultation, and that patients are typically much more willing to consider a psychosocial explanation for their symptoms than the literature might suggest [17].

The perception of a fundamental difference in beliefs is likely to be one important reason why neurologists describe the process of communicating the diagnosis of NES as "negotiating a minefield" [18]. A protocol for the explanation of the diagnosis of NES has been proposed [19], but its effectiveness or acceptability has never been tested in a prospective or controlled fashion.

A mode of communication that enables patients to comprehend the nature of their seizures is very important because it is likely to affect clinical outcome. Whereas NES can resolve completely after the explanation by the doctor [20], outcome is significantly worse in patients who continue to think that they have epilepsy [21,22]. Some report feeling angry and confused after receiving the diagnosis [21,23,24], and unsuccessful communication is likely to increase the risk of continuing inappropriate treatment with

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anticonvulsants. It is interesting that 41% of patients diagnosed with NES (and no additional epileptic seizures) were still found to be taking antiepileptic drugs a mean of 4 years after the diagnosis of NES had been communicated to both them and their primary care physicians [25]. Patients are also unlikely to engage with psychological treatment if they continue to think that they should be treated with antiepileptic drugs.

To date there is very limited information about patients' experience of receiving the diagnosis which makes it difficult to improve the communication process. This study uses a qualitative methodological approach, interpretative phenomenological analysis (IPA), to enhance our understanding of this experience. IPA is particularly suitable for exploring people's experiences and "inner world," and has been widely used in health psychology and clinical research [26].

2. Patients and methods

2.1. Participants

Consecutive patients who had received the diagnosis of NES at the Royal Hallamshire Hospital in Sheffield were considered for inclusion in this study. The diagnoses were based on all available clinical information (including ictal video/EEG recordings in some patients) and made and communicated by one of three fully trained neurologists with a particular interest in seizure disorders. Patients were recruited from a waiting list for psychotherapy and interviewed before their first meeting with a psychotherapist. Patients were excluded if they were under the age of 18, not fluent in English, or had major neurological problems other than NES (including concurrent epileptic seizures), learning disability, or a physical or disabling illness. All participants gave written informed consent before the interview commenced. The interviewer was a woman of white European origin in her thirties. She was a final-year trainee clinical psychologist who had no personal experiences of chronic or medically unexplained illness.

The sample size was in the range recommended for IPA studies [27]. The data presented here are part of a larger project that encompassed equivalent analyses of interviews with the neurologists involved in the communication of the NES diagnosis at the center [18].

2.2. Procedure

The semistructured interviews were audiotaped. Open-ended questions and prompts were used in accordance with guidelines provided in Ref. [28]. The Appendix provides further details of the interview outline. Although the interviews were guided by the outline, there was flexibility to allow interviewees to lead the discussion and talk about the issues that were most important to them.

2.3. Data analysis

Audio recordings were transcribed verbatim. In line with established IPA methodology, the transcripts were read through several times to record initial ideas and reactions to the data [29,30]. Themes that emerged as representative of the content were then identified through further examination of the text, and were illustrated using quotes. As each interview was examined new themes were added to the list. Finally, "clusters" of related themes were identified.

2.4. Quality and validity

Yardley's principles of sensitivity to context, commitment and rigor, transparency, and coherence [31] were followed while col-

lecting data, carrying out the analysis, and writing up the findings. Sensitivity to context was achieved through reflexivity: an assessment was made of the possible impact of the assumptions, experience, and characteristics of the researcher and the methods used on the data collected. This involved the use of a reflexive research journal to document such issues as they arose and an explicit discussion of this area in the writeup.

The thematic structures assembled from the interviews were presented to two of the interviewees for comment on how the interpretations related to their own experiences. The results of this process were used in the continuing analysis of the interviews. This "member validation" is considered a suitable method of enhancing the validity of qualitative research findings [32].

3. Results

3.1. Demographics

Eight women of white European origin took part. Two further patients expressed an interest in participating, but subsequently withdrew before the interview was carried out (for additional clinical and demographic information, see Table 1).

Interviews lasted between 25 and 120 minutes. Six main themes and associated subthemes emerged. Two themes were related to the nature of NES (Table 2), and four to the impact of receiving the diagnosis (Table 3). Tables 2 and 3 provide an overview of the themes, subthemes, and illustrative quotes. It is recognized that there is a degree of overlap between the themes. The illustrative quotes have been edited in places to preserve anonymity and facilitate comprehension. In the following description of the themes, the numbers in parentheses refer to typical quotes from the tables.

3.2. Themes relating to the nature of NES and living with the condition

3.2.1. The experience of living with nonepileptic seizures

This theme provides an insight into the lives of people living with NES and represents the basis from which the individual goes on to experience the diagnostic process. Four participants volunteered information about their experiences of trauma during childhood, including accounts of sexual, physical, and emotional abuse. This issue was rarely explored in detail (2.1). Seven participants discussed stressful life events at the onset of seizures, including domestic abuse and mental health problems. Seizures were considered to have an unreal, strange quality, described by Susie as "like altered consciousness" (2.2, 2.3). Seizures were considered by all to have a negative emotional impact: both Emily and Rachel summed up the experience as "horrible" (2.4). The language used by participants suggested that they felt overpowered by the seizures and that they remained passive and helpless throughout (2.5, 2.6). For many, the helplessness was also about feeling trapped by the seizures, and resonated for some in their interactions with medical professionals (2.7).

Table 1

Clinical and demographic information (all patients were female).

Pseudonym	Age	Number of years since onset of NES
Sharon	Thirties	21
Emily	Twenties	1
Mabel	Sixties	5
Lucy	Forties	7
Angela	Thirties	14
Jenny	Thirties	15
Rachel	Twenties	2
Susie	Forties	20

Table 2
Themes, subthemes, and typical statements relating to the nature of NES and living with the condition.

Main theme	Subtheme	Typical statement
Experience of living with NES	Living with trauma	(2.1) "What I do remember I don't want to remember ... so I just leave it there." [Lucy]
		(2.2) "... like altered consciousness." [Susie]
	Altered consciousness	(2.3) "It was like a cartoon movie that had been slowed down, that's how I felt." [Susie]
		(2.4) "It wrecks your life." [Sharon]
		(2.5) "It's as if I've been unplugged." [Emily]
	Helplessness	(2.6) "You dread it ... you think 'no not today, I don't want this today.'" [Sharon]
		(2.7) "Nobody ever tells you anything at hospital." [Emily]
		(2.8) "Cos I used to be 'boom' [punches air with hands] ... but since all this, it just kicked a lot more stuffing out of me than I tend to realize." [Lucy]
	Loss	(2.9) "It's wrecked my life. I wanted to study, I wanted to be a nurse ... I've had to give everything up because of these stupid seizures. ... It's all gone." [Angela]
		(2.10) "You feel like it's only you, there's only you going down that road." [Lucy]
	Isolation	(2.11) "People tended not want to be around you ... you'd have a fit, spoil their evening, so ... I ended up having a very small circle of friends." [Susie]
		(2.12) "I just don't have anybody to tell really." [Emily]
(2.13) "I wasn't actually sure that it was epilepsy." [Lucy]		
Label and understanding	Search for a label	(2.14) "I used to think I'd got a brain disease." [Sharon]
		(2.15) "'Seizures' is just something that I just call them just so that I can say what they are really." [Emily]
	Meaning of NES	(2.16) "It makes a lot of sense, it just makes a lot of sense why I've got this." [Jenny]
		(2.17) "I love the diagnosis, because that means there's no brain damage ... it's just psychological." [Susie]
		(2.18) "So what's caused me to have that seizure if nothing's reminded me of any trauma in my past? ... It just doesn't make sense." [Angela]
	Healing the scar	(2.19) "I just can't wait to start ... get ball rolling ... treatment and things." [Jenny]
		(2.20) "I don't want a quick fix ... this has got to be addressed in a different way." [Susie]
		(2.21) "I can't see how talking to somebody is going to fix it." [Emily]
	Label as a beginning	(2.22) "How can you sit and talk to somebody about something that you have no control over anyway ... I don't think we'll ever get to the bottom of it really." [Lucy]
		(2.23) "I mean at least I've got a future; I can get better now because for the last fifteen years I was just virtually staying the same." [Jenny]

Loss resulting from NES featured heavily in the lives of all participants. Losing control during the seizure itself was one way in which this manifested, contributing to the sense of helplessness (2.8). Loss of independence and role were very salient issues. Loss of a previous way of life and even loss of a way of feeling like a person were also cited (2.9). Five participants talked about a sense of isolation. This situation resulted in some becoming more withdrawn and less likely to discuss their illness with others, with the potential for a vicious circle of isolation (2.10–2.12).

3.2.2. Label and understanding

The issue of understanding the cause of the seizures was salient for all interviewees. Most had developed labels for and hypotheses about the cause of the seizures prior to receiving the diagnosis (2.13, 2.14). Where no conclusion could be reached, the patient might decide on a temporary label to facilitate communication with others about the illness (2.15). Interviewees ascribed different meanings to the new diagnosis. For some, it was embraced with enthusiasm and a notion that they finally had an answer with which they could identify and which made sense in the context of their lives (2.16). A positive interpretation of the diagnosis was also made by some who saw it as good news because of the alternative, more threatening explanations (such as "brain damage") that it ruled out (2.17). Others appeared to struggle more to apply the diagnosis to their lives and to make their own sense of it, or could not understand the diagnosis or apply it to their lives at all, and hence rejected it (2.18).

The meaning that was made of the diagnosis had a significant impact on attitude toward treatment offered to help "heal the scar" (Susie). For participants who had developed internal models of how the seizures related to past experiences, the relevance of psychotherapy and the rationale for undertaking it were straightforward (2.19, 2.20). In contrast, for those who found it more difficult to see the relevance of the diagnosis to their lives and to understand how the seizures could have a nonphysical cause, the

rationale for treatment was beyond comprehension (2.21, 2.22). For some, the diagnosis represented a starting point from which they could get on with the rest of their lives (2.23).

3.3. Themes relating to the impact of the diagnosis of NES

3.3.1. Being left in limbo land

There were three distinct periods when a sense of "being left in limbo land" (Angela) was most strongly felt: when the seizures started and the cause was unknown (3.1, 3.2), when medical investigations into the cause were unfruitful and the individual was discharged without answers, experienced by Susie as being "dumped" (3.3, 3.4), and the interval between diagnosis of NES and commencement of treatment (3.5, 3.6). The theme of a sense of being in limbo seemed to be strongly related to the sense of helplessness engendered by the seizures. Participants reported that their lives took on a static quality from the point at which their seizures started and they did not feel able to move forward until they understood the cause. The participants had experienced the seizures for between 1 and 21 years and had received the diagnosis of NES within the preceding 6 months. During the intervening time most had undergone a variety of investigations that had ruled out other diagnoses but provided no further explanations. Many spoke of these earlier experiences and how they had shaped their attitude to their illness and to medical professionals. Some described going through several cycles of having their hopes raised that a cause might be found, only to be discharged back into a state of limbo and confusion. The final point at which there was a sense of limbo was between receiving the diagnosis and the start of treatment. Participants discussed the negative emotional implications, in some cases resulting in a sense of great distress and desperation, of this long wait (3.5, 3.6). There was a consensus that this wait should be reduced or further support offered (described by Susie as a "lifeline") during this period of limbo.

Table 3

Themes, subthemes, and statements relating to the impact of receiving the diagnosis of NES.

Main theme	Subtheme	Typical statement
Being left in limbo land	When you don't know what it is	(3.1) "Just left in limbo land wondering what's gonna happen." [Angela] (3.2) "When you don't know what it is you're just kind of stopped in this like zone ... you just feel quite trapped." [Emily]
	Being dumped	(3.3) "I was discharged again without any explanation and just left ... it was frustration, it was anger, it was well, am I just wasting people's time? You just feel like you've been dumped." [Susie] (3.4) "I was going to the pain clinic and they've said they can't treat me. I was seeing the psychiatrist, she doesn't see me because I'm waiting for [psychotherapy] ... I think [my GP counsellor's] finishing. She wanted to get somebody more qualified than her." [Angela]
	The wait for treatment	(3.5) "I've got to wait nearly a year to get sorted out." [Emily] (3.6) "I've took overdoses before ... if something doesn't happen soon to let me get a better quality of life back, I won't be here." [Angela]
Doubts and certainty	Doubt	(3.7) "I'm thinking 'well he's right...' and some days I think he's wrong." [Sharon] (3.8) "You've just got to try these things and if that's what they say will help me ... but I don't think it'll work" [Emily] (3.9) "You start to think, 'well why aren't they finding anything, am I making it up, or is there something I can do myself to stop it?" [Emily] (3.10) [The neurologist] "says he wants me to come off the tablets when I start seeing [the psychotherapist] ... although I can't understand how the tablets actually improved the seizures if it's caused through trauma." [Angela]
	Certainty	(3.11) "It was so pleasing that someone could sit and listen to my story, and ... say, 'oh I know exactly what that is.'" [Susie]
Feeling like a human being again	Through the relationship with the neurologist	(3.12) "He's taken more interest in me than anybody else has." [Mabel] (3.13) [The neurologist] "made me feel very different than anyone else had ... he is interested, and that felt really good." [Susie]
	Through receiving the diagnosis	(3.14) "It's not in my mind, I'm not making it up. That all I was bothered about really ... there is a reason why this is happening." [Jenny] (3.15) "I'm thinking, 'yes! yes! somebody believes me.' It just made me feel ... a genuine person." [Susie]
	Through the research interview	(3.16) "Someone saying 'I'm interested, can I come and talk?' What? You're interested in me? You're interested in my illness? ... after twenty years, to talk about how I feel and how I were made to feel by different people in the profession ... it helps me understand how I've felt as well." [Susie]
Emotional impact of diagnosis	Relief	(3.17) "So now, that burden that I've carried round of, 'it's all my fault,' it isn't." [Susie]
	Confusion	(3.18) "I don't know where my head were to be honest ... [it] was just all over place." [Sharon]
	Happiness	(3.19) "I was happy that I knew there was a future, a good future, that there could be a new me and things like that." [Jenny]
	Unaffected	(3.20) "Just something and nothing ... something out of the blue." [Mabel]
	Anger	(3.21) "I'd like to get the first doctor who diagnosed me and strangle him (laughs) ... it just made me angry ... and I think I always will be." [Angela] (3.22) "And I felt angry, I felt anger coming into my tears for my dad, cos it's my dad that's the main person that's done all this." [Susie]
	Upset	(3.23) "It's like my abuser's still got a lot of control over me really ... it's been hard, upsetting ... I feel I'm still getting punished." [Jenny]
	Despair	(3.24) "They wonder now why I'm depressed. I'm depressed because I know my life's been wrecked from misdiagnosis. ... Oh dear." [Angela] (3.25) "Is ending your life something that you've thought about?" "Yeah. A lot since I were given this diagnosis." [Angela]

3.3.2. Doubt and certainty

All but one of the participants expressed a sense of doubt. Doubt could be categorized in terms of source and target: doubt of others by the patient (3.7, 3.8), doubt of the patient by others (3.9), and also ultimately, self-doubt (3.10). Doubts were voiced about doctors involved in the patient's care, specifically regarding the accuracy of the diagnosis of NES, which had clear implications for the patient's attitudes and beliefs regarding the treatment being offered. The continued prescribing of antiepileptic drugs cast particular doubt on the doctors' certainty regarding diagnosis (3.10). The perception that the reality of their illness was doubted by medical professionals and society in general was identified by five participants. One participant stated that doctors consider only epileptic seizures as "genuine." Perceptions of doubt from society and even friends and family were reported to contribute to feelings of isolation and distress. For some, perceptions of external doubt seemed to contribute to the emergence of self-doubt and confusion. Several of the participants indicated that the perceived certainty with which the neurologist delivered the diagnosis was central to their subsequent appraisal. They found the certainty to be reassuring and a relief after all the uncertainty they had experienced, as well as to help them to believe that the diagnosis was correct (3.11). However, the beneficial influence of certainty could

be diminished where beliefs about certainty had been compromised in the past.

3.3.3. Feeling like a human being again

All participants contributed to this theme of validation. It has strong links to the first theme (the experience of having NES), in particular to some of the isolating aspects of the experience. Some features of the diagnostic process had the potential to diminish or reverse these effects. The positive nature of the relationship with the diagnosing neurologist was commented on by six interviewees, often because it was unexpected. Many participants perceived that the neurologist made an effort to be pleasant and approachable, giving an impression of being interested in the patient by making time to explain the diagnosis and answer questions (3.12, 3.13). Receiving the diagnosis was experienced as validating by some. This could be in the form of internal validation, in that the participant's experiences of the seizures were confirmed and the feelings of self-doubt could be rejected (3.14, 3.15). Taking part in the interview was also experienced as validating by some (3.16).

3.3.4. Emotional impact of diagnosis

A range of emotions following diagnosis were described, leaving some participants tearful and overwhelmed. An immediate feeling

of relief was described by five interviewees. This was attributed to the knowledge that the cause was not something more sinister, such as epilepsy (3.17), and to the feeling of certainty that the problem was now known after so much uncertainty. A further source of relief for some was the perception that the diagnosis absolved them of blame for the seizures: the explanation implied that the seizures were caused by the brain's attempts to cope with trauma and, hence, were beyond conscious control. This allowed the cause to be externalized, as "the brain" causing the seizures or, where appropriate, the person considered to be responsible for the initial trauma. A sense of confusion was reported by five respondents, associated with attempts to take in the information about the cause of their seizures and make sense of it (3.18). Happiness and hope about the future were also expressed (3.19). For two participants there was a sense that the diagnosis was meaningless and that they were relatively unaffected by it: on reflection, Lucy felt that it had made no difference to her experience of the seizures and that it had failed to provide her with a satisfactory explanation for their occurrence (3.20). Mabel perceived that the seizure that had occurred while she was being monitored was qualitatively different from those that she usually experienced (which she continued to believe were epileptic).

Anger was referred to by the majority of participants. Three introduced the issue of anger only to deny having felt it. For Angela, the anger was directed at the doctor who originally gave her the epilepsy diagnosis (3.21), whereas for Susie, the explanation of the diagnosis brought to mind her experiences of abuse as a child and she felt anger toward the perpetrator (3.22). Two other participants felt renewed distress about their abusers on receiving the diagnosis and a trauma-related explanation for their seizures (3.23). Angela felt "weak" because something from her past was getting to her. Jenny felt she was "still getting punished." For Angela in particular, the diagnosis led to a strong feeling of despair resulting in thoughts of suicide (3.24, 3.25).

3.3.5. Feedback on analysis

An earlier draft of this analysis was presented to two of the participants for their thoughts and comments in separate meetings arranged for this purpose. Emily and Susie were approached for feedback because their prediagnostic experiences had been very different and also because their interviews had taken place near the beginning and the end of the interviewing process. During these meetings it was emphasized that not all aspects of the thematic structure would necessarily apply to them. Nevertheless, both interviewees stated that they felt that the interpretations of what they had said in the interviews were valid.

4. Discussion

Given the importance of the successful communication of the diagnosis of NES, there is surprisingly little research on what it is like for patients to receive this diagnosis. Only three articles touch on the experience. The first study used IPA to explore illness representations in patients who had just received the diagnosis of NES [24]. Participants were asked to give an account of their illness and then questions were posed that guided the interviewee to focus on the five elements of Leventhal's self regulation model (identity, cause, timeline, consequences, and controllability) [33]. The authors concluded that patients' illness perceptions could be categorized in terms of the five elements, although two additional themes, "feelings about the situation" and "acceptance of others," also emerged from the data, suggesting that the model did not fully represent the phenomenon. The second study aimed to assess patients' understanding of and reaction to the diagnosis of NES and to explore whether these contribute to outcome [21]. Information

was collected from 84 participants, 1 to 7 years after diagnosis, using a short, semistructured telephone interview. At the time of the interview, which took place after any psychological follow-up, only a third of participants were judged to have an understanding of the diagnosis (defined as an awareness that the seizures were due to psychological factors). A similar number recalled being confused when they received the diagnosis, and one-fifth described reacting angrily. Both of these reactions were found to be associated with a poorer outcome in terms of seizure frequency at the time of interview. In contrast, a feeling of relief (noted by one-fifth of participants) was associated with a more positive outcome. The final study contained a brief enquiry about reaction to the diagnosis as part of a telephone-based structured interview designed to investigate clinical, psychiatric, and psychosocial characteristics of this patient group [34]. The participants were 56 patients who had received the diagnosis an average of 18 months previously in a manner that was informed by the communication protocol discussed above [19]. Anger and relief were the only emotional reactions identified, cited by 13 and 21 participants respectively. Belief in the diagnosis was found to be associated with improved outcome, and an angry reaction did not predict a poorer prognosis.

Although all of these studies suggest that the patients' perspective on the event of diagnosis delivery has an impact on outcome, they provide only limited insights into the experience of receiving the diagnosis and do not tell us why some patients were left confused or angry whereas others felt relieved. The largest study was conducted such a long time after patients had received the diagnosis that their responses are likely to have been affected by intervening events (including psychotherapy). All previous studies were limited in their qualitative scope by being based on fairly rigid interview schedules or by being underpinned, a priori, by one particular psychological theory (the self-regulation model).

The current study identified six main themes. "The experience of living with NES" appeared to be inseparable from the participant's personal background, often involving a history of trauma or ongoing psychological stress, confusion, helplessness, loss, and isolation. Perhaps even more than in other medical areas, the process of reaching and communicating the diagnosis of NES has to be understood in the context of patients' preexisting vulnerabilities. As a group patients with NES have been shown to be characterized by borderline-like personality features [35], predominantly avoidant coping [36], and insecure attachment styles [37]. The trajectory of the patient's condition does not begin with diagnosis, but prediagnosis experience shapes and frames the postdiagnosis response [38].

For some participants the process of achieving a "label and understanding" provided legitimacy, a language to facilitate discussion of the illness and reassurance that the cause was not more sinister. It was also associated with a treatment that was perceived to be potentially helpful. These effects of receiving a diagnosis have previously been described in physical disorders diagnosed after long delays [39]. However, in contrast to these more objectifiable disorders, the issue of the diagnosis providing meaning was less straightforward. In accordance with findings in another medically unexplained disorder (fibromyalgia), acceptance of the diagnostic label was related to concordance between diagnosis and experience of illness [40]: only those participants who were aware of a history of previous trauma seemed to acquire a sense of meaning. However, the construction of personal meaning (integrating the diagnosis into personal narrative) appeared central to acceptance of the diagnosis. Failure to understand the diagnosis resulted in its outright rejection for two of the eight participants and doubts about it and, therefore, about the suggested treatment.

The experience of "being left in limbo land," perhaps felt most clearly after diagnosis and before commencement of psychotherapy, may not be specific to the diagnosis of NES: it has also been

described in patients diagnosed with multiple sclerosis [41], and following the diagnosis of type 2 diabetes [42]. However, the interaction of the sense of feeling “dumped” and patient’s previous or current life experiences seemed to have particularly dramatic emotional consequences in the NES group, including fears of a nervous breakdown and thoughts of suicide.

Participants made a wide range of statements relating to “certainty and doubt” about their seizures. Doubt about the diagnosis seemed to interact with doubt about the nature of the condition or feelings of self-doubt and self-blame or guilt. Such more general doubts have been found to be associated with an increased risk of affective disorders in other medically unexplained conditions [43]. Especially in the patient group studied here, it is possible that these feelings were related to the experience of abuse, which can evoke a tendency in victims to blame themselves for what has happened [44].

The implications of the three themes of experience, limbo, and doubt were illustrated in descriptions of the “emotional impact of the diagnosis.” Relief, anger, and confusion were described by many participants, reflecting previous findings with this patient group [21,34,45]. Relief was associated with the knowledge that the seizures did not have a more sinister cause and the sense that a burden of responsibility had been lifted (allied to the neurologist’s externalizing framing of the diagnosis). Confusion reflected the difficulty that participants described in taking in all the information and making sense of it within the consultation. Anger was felt toward previous doctors and also toward perpetrators of abuse (although, interestingly, it was not recalled as being directed toward the doctor in the consultation). Our findings add four emotional reactions to those cited in the literature: happiness, apparent lack of affective response, distress, and despair. Happiness resulted from the relief at the diagnosis, but also reflected a new hope about the future. An “unaffected” reaction was associated with a feeling that the new label failed to provide an explanation for the seizures and that the diagnosis was wrong. Distress was caused by the unexpected reintroduction of the specter of abuse and associated emotions, resulting from the explanation that the seizures might be caused by past abuse or trauma. Despair was brought about by strong feelings of loss and hopelessness, and could potentially lead to thoughts of suicide.

Receiving the diagnosis could also elicit the more complex reaction of “feeling like a human being again.” The diagnostic consultation was found to have the potential to empower patients by validating their condition, through the unexpected experience of a positive relationship with the neurologist, the explanation of the seizure experiences, and the sense that they were believed. Such a process is likely to have positive implications for engagement with services and in patients’ attitudes toward health professionals. The research interview was also a source of social validation and a valued opportunity for some to process the experience and meaning of diagnosis. This observation suggests that a fairly brief intervention giving patients the opportunity to discuss their thoughts and feelings about their new diagnosis could be effective.

4.1. Limitations

This study has a number of methodological limitations. The qualitative approach required a small sample size. It is recognized that NES are an etiologically and clinically heterogeneous disorder [46], and it may be that our sample did not capture the complete range of possible responses to the diagnosis. All patient participants were female. There are suggestions of important gender differences in NES [47], and we cannot comment on the reaction of male patients to the diagnosis. None of the participants were thought to have coexisting epilepsy although additional epileptic

seizures are observed in 10–30% of patients with NES [7]. Patients with combined epileptic and nonepileptic seizures may have particular difficulties with understanding the diagnosis of NES. Interviewees may have had different experiences leading up to the diagnosis of PNES, including the use of provocative techniques, and these may have influenced their statements. All participants were recruited from a waiting list for psychotherapy. This means that we cannot describe findings in patients who had refused referral for psychological treatment. The excluded group is likely to have consisted of individuals who were the most unconvinced by a psychological explanation or most angry at the diagnosis, and their perspectives of the experience would have been of great interest. Future qualitative research might usefully focus on this group. The findings are based entirely on what the interviewees said, and the reliability of their statements cannot be validated. Finally, our study did not include any outcome measures, so we cannot be certain about the effects of the perceptions on the patients’ further illness trajectory (including engagement in psychotherapy). However, the findings of our study provide a basis for future hypothesis-driven research in this area.

5. Conclusion

Despite these limitations, the findings of this study have direct implications for clinical management. The question of whether the neurologist should mention a possible link between trauma (including childhood sexual abuse) and NES has been discussed controversially in the previous literature [19,23,45,48]. Our results suggest that making this link was vital for some participants in understanding and therefore accepting the diagnosis. However, the suggestion of an association of NES with previous trauma allowed other patients to reject the diagnosis of NES, because they were not aware of any significant trauma in their personal history. It therefore seems a good idea for neurologists to make references to trauma, but not to be too specific and to stress that NES can also occur in the absence of trauma. Furthermore, neurologists need be more aware of the emotional consequences for patients of making the link between previous trauma and ongoing seizures. Most participants in this study described feelings of anger, shame, and/or helplessness; some expressed suicidal ideas. This means that there is a clear need to drastically reduce the length of the “unsupported” period that currently exists between diagnosis and the onset of treatment. This might be achieved through the offer of an early follow-up appointment with the neurologist, initiatives to reduce the waiting time for psychotherapy, or the introduction of an alternative source of support during the period of waiting. A previous study has suggested scheduled contacts with a medical social worker at 3 and 12 months after diagnosis [49]; another suggested the involvement of a “psychiatric consultation liaison nurse” [23].

Our results also demonstrate how difficult it is for patients to take in the neurologist’s explanation of the diagnosis of NES. Copying the patient into a detailed letter about the consultation [50] or providing written information about the disorder may help [51].

Finally, our findings suggest that patients may welcome the provision of programs that could combat isolation. Although leaflets about the condition may help with this, group treatments may be particularly welcome by some patients [52–54]. One participant suggested that it might be helpful to have a letter from an individual who has gone on to have a “good outcome” describing the process by which he or she got there.

Appendix . Interview schedule

I am interested in talking to people who have been told that their seizures are not due to epilepsy, in order to gain some under-

standing of what this experience is like and what it has meant for them and their lives.

1. Could you tell me a bit about yourself and your experiences up until you were told that your seizures are not due to epilepsy?

What was life like? (background, including relationships, work, health, etc.)

How did you see yourself?

Did you talk to other people about your seizures?

2. Can you remember what you were thinking when you arrived for the appointment at which you were told that your seizures aren't due to epilepsy?

What were you expecting to happen?

How did you feel about that?

Who was there?

3. What happened at that appointment?

What went through your mind at the time?

What was it like mentally/emotionally/physically?

What did you say?

Did the doctors give you an explanation for your seizures?

How did the appointment end? How long did it last?

Could anything have been different?

How did you feel later that day/week?

4. Have you told anyone about this diagnosis?

Who?

What did you tell them?

What did they think?

5. What has happened since then?

What do you think about it now?

What do you feel about it now?

How are things now—frequency of seizures, medication?

6. Is there anything else you think might be helpful for me to know?

What was the interview like?

Did anything surprise you?

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