Article:

Peacock, M., Bissell, P., Ellis, J. et al. (4 more authors) (2023) 'I just need to know what they are and if you can help me': medicalization and the search for legitimacy in people diagnosed with non-epileptic attack disorder. Epilepsy and Behavior, 148. 109485. ISSN 1525-5050

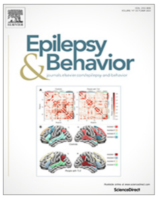
https://doi.org/10.1016/j.yebeh.2023.109485

Epilepsy & Behavior 148 (2023) 109485

Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh



‘*I just need to know what they are and if you can help me*’: Medicalization and the search for legitimacy in people diagnosed with non-epileptic attack disorder

Marian Peacock [a,*], Paul Bissell [b], Julie Ellis [c], Jon M Dickson [d], Alistair Wardrope [e,f], Richard Grünewald [g], Markus Reuber [g]

[a] *Edge Hill University, Faculty of Health, Social Care & Medicine, St Helens Road, Ormskirk L39 4QP, UK*
[b] *University of Chester, Chester, UK*
[c] *Ramsden Building, University of Huddersfield, Queensgate, Huddersfield HD1 3DH, UK*
[d] *The Medical School, The University of Sheffield, Samuel Fox House, Northern General Hospital, Herries Road, Sheffield S5 7AU, UK*
[e] *Department of Neuroscience, The University of Sheffield, Sheffield, UK*
[f] *Department of Clinical Neurology, Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, UK*
[g] *Academic Neurology Unit, University of Sheffield, Royal Hallamshire Hospital, Glossop Road, Sheffield S10 2JF, UK*

ARTICLE INFO

Article history:
Received 5 July 2023
Revised 14 September 2023
Accepted 7 October 2023

Keywords:
Non-epileptic attack disorder (NEAD)
Functional seizures
Medicalization
Legitimacy

ABSTRACT

This paper focuses on the struggles for legitimacy expressed by people with non-epileptic attack disorder (NEAD), one of the most common manifestations of functional neurological disorder presenting to emergency and secondary care services. Nonepileptic attacks are episodes of altered experience, awareness, and reduced self-control that superficially resemble epileptic seizures or other paroxysmal disorders but are not associated with physiological abnormalities sufficient to explain the semiological features. “Organic” or medicalized explanations are frequently sought by patients as the only legitimate explanation for symptoms, and consequently, a diagnosis of NEAD is often contested.

Drawing on narrative interviews with patients from a small exploratory study and using a sociological perspective, we propose that a psychological account of NEAD does not provide a sufficiently legitimate path into a socially sanctioned sick role. This is a reflection of the dominance of biomedicine and the associated processes of medicalization. These processes are, we argue, the sole route to achieving legitimacy. The stress-based or psychologically oriented explanations offered to patients in contemporary medical models of the etiology of NEAD engender an uncertain identity and social position and fail to provide many patients with an account of the nature or origin of their symptoms that they find satisfactory or convincing.

These struggles for legitimacy (shared by others with functional or somatoform conditions) are sharpened by key features of the contemporary healthcare landscape, such as the increasing framing of health through a lens of ‘responsibilization’.

1. Introduction

Non-epileptic attack disorder (NEAD) is characterized by episodes of altered experience and reduced self-control that superficially resemble epileptic seizures or other paroxysmal disorders but are not associated with physiological abnormalities sufficient to explain the subjective and objective seizure manifestations. The uncertain social and medical framing of this disorder is reflected by the fact that it has many names, including psychogenic non-epileptic seizures, conversion seizures, or functional/dissociative seizures. The term NEAD is used here because this was the most commonly used terminology in the United Kingdom (UK) at the time of the study, the label most familiar to the participants in this project, and the most commonly used term in the interviews.

Most experts interpret the manifestations of NEAD as dissociative responses to external or internal triggers of emotional arousal [1]. Due to the high morbidity associated with NEAD [2,3] many

---

* Corresponding author at: Senior Lecturer in Public Health, Edge Hill University.
E-mail addresses: m.peacock@sheffield.ac.uk, peacockm@edgehill.ac.uk (M. Peacock), p.bissell@chester.ac.uk (P. Bissell), j.c.ellis@hud.ac.uk (J. Ellis), j.m.dickson@sheffield.ac.uk (J.M Dickson), a.wardrope@sheffield.ac.uk (A. Wardrope), r.a.grunewald@sheffield.ac.uk (R. Grünewald), m.reuber@sheffield.ac.uk (M. Reuber).

https://doi.org/10.1016/j.yebeh.2023.109485
1525-5050/

people are either unable to work or experiencing significant restrictions in everyday life [4]. High numbers of somatic symptoms, avoidant coping tendencies, difficulties in describing and accessing emotions (alexithymia), and comorbidities such as depression, anxiety, post-traumatic stress disorder (PTSD), and chronic pain [5] are all associated with NEAD. It is also linked to high rates of a broad range of medical disorders and a hazard ratio of premature death of >3—closely linked to the high prevalence of other medical disorders, including cardiovascular, endocrinological, and respiratory diseases [6].

Differentiation from epilepsy can be difficult; many patients only receive the diagnosis of NEAD after an initial misdiagnosis of (and inappropriate treatment for) epilepsy. The use of epilepsy treatments for patients with NEAD (especially in emergency settings) puts patients at risk of iatrogenic injury, including death [7]. Furthermore, the initial focus on biomedical investigations and the process of exclusion of "organic" explanations may contribute to resistance to treatments that may be of value for NEAD (such as psychotherapy) when they are eventually proposed [8]. The transition from an "organic" diagnosis (with investigationally-demonstrable ictal physiological changes) to a "psychological" diagnosis is often particularly challenging for those "undiagnosed" with epilepsy [9], especially given the conflict between psychologizing explanations and ostensibly "physical" manifestations.

We would like to clarify that our use of the term "organic" here and the functional/organic distinction serves as shorthand for the conceptually problematic but widely employed boundary drawn between those conditions that are given pathophysiological and mechanistic explanations, and those that are not. The latter are usually modeled instead in psychological terms [10]. We recognize that this distinction implicitly demands a substance dualism that we do not endorse as an ontological proposition, but the widespread employment of this dichotomy by medical professionals, patients/participants, and wider society makes it essential to this paper. We have therefore used these terms in inverted commas to reflect our acknowledgement that this is a contested, and at times unhelpful, dichotomy.

Around three-quarters of those with a diagnosis of NEAD are women. NEAD is linked with histories of neglect, trauma, or conflict in childhood, including childhood sexual abuse (CSA) (reported by 20%–30% of women and 5% of men in different patient cohorts [11,12]). Increased rates of adverse life events and traumas in adulthood are also found among those with NEAD [13], including events precipitating the onset of the disorder [14]. However, around a third of patients do not report trauma or adverse events [15]. This may be because trauma is not present; alternatively, it may be present but not understood as trauma by the person or not readily reported in a clinical or research setting.

NEAD is unusual amongst functional conditions in that, for some patients, investigations using simultaneous video- and electroencephalography (EEG)-recording of a typical witnessed seizure can confirm the absence of a currently identifiable pathophysiological mechanism with a high degree of certainty. While patients diagnosed with other conditions categorized as somatoform (e.g., fibromyalgia) may, in the absence of confirmatory investigations, resist "psychological" explanations, video-EEG demonstration of the non-epileptic basis of NEAD diminishes this possibility. In contexts where legitimate suffering is equated with biological dysfunction, this may deprive those with NEAD of the *"claim to exemption"* and *"permission to be ill"* [16] that the *"sick role"* provides [17]. In a previous paper, we concluded that the Free Association Narrative Interview (FANI), the narrative methodology we employed in the present study [18], facilitated access to narratives that can provide new insights into NEAD. More specifically, we identified the role of 'trauma denied' or 'unacknowledged' and of patients' complex diagnostic journeys in their experience of living with this disorder [19]. In the present paper, we use a sociological perspective to focus on legitimacy and the place of medicalization, themes present throughout the data.

2. Methods

2.1. Setting and participants

In this exploratory study, we intended to investigate what the FANI method may be able to add to understanding NEAD. Ethical approval was obtained from the NHS Research Ethics Service (NRES) Committee, Yorkshire & The Humber-Bradford Leeds.

We recruited participants from routine hospital attendances at a single center (Sheffield, UK), inviting all attendees with a diagnosis of NEAD. Such diagnoses were made by an NHS consultant neurologist with a special interest in epilepsy on the basis of seizure descriptions as well as relevant investigations, including: magnetic resonance imaging (MRI) of the brain (to exclude structural abnormalities of the brain that would be more likely to be associated with epilepsy than NEAD); EEG; and video or video-EEG recordings of typical seizures [20]. Clinicians initially obtained consent from patients for a Research Fellow (MP) to contact them; all who gave consent to contact were invited to interview. Five individuals agreed to take part in face-to-face interviews (up to three interviews per person, with all participants being interviewed at least twice). Three participants chose to be interviewed in their own homes and two in hospitals.

2.2. Data collection

The interviews used the FANI approach, aiming to elicit narratives on the terrain of the narrative giver [18]. This entailed the use of a topic guide to ensure all areas of interest were covered, but in the order that these topics naturally arose. Each interview lasted between 1 and 2 hours, with the interviewer proposing a conclusion at the two-hour point, if necessary. Questions were open and limited in number, and participants were free to raise issues salient to them. Prior to the second interview, the RF refined the topic guide on the basis of the initial interview to ensure that all areas were covered within the two interviews.

In addition to interview recordings, the dataset included reflexive notes kept throughout the study and a range of materials (emails, texts, written notes, etc.) provided spontaneously by participants.

2.3. Analysis

Following interview recording and verbatim transcription, we analyzed the data using FANI principles. One author [MP] conducted primary analysis, subsequently refined within a data analysis group comprising two specialist neurologists [MR and RG], an academic GP with a special interest in neurology [JD], a specialist neurological psychotherapist, a medical sociologist [PB], and the research fellow [MP].

Narrative approaches, of which FANI is one, view the story as something greater than the sum of its component parts. The whole story and how it is told provide us with more than data fragments can. The investments of participants in aspects of their narrative, the discourses that are drawn on in the story's creation, and other materials are available for scrutiny and analysis. In addition to what we can understand from the focus on the whole story, there are also what Jovchelovitch and Bauer term *"indexical statements"* in narratives [21]. These are references to concrete and identifiable events located in time and place that connect narratives to the wider world, including political and social contexts. As Frank [22] has argued, in the case of illness narratives, stories reflect what is possible and permissible in talking about how illness could and should be described in the cultures within which the story is located. Our theorizing arose from the study data and was grounded in these ways of working with the data.

3. Results

3.1. Participants

Participant pseudonym (age, gender)	**Relationships**	**Response to diagnosis**	**Own understanding of symptoms**	**Trauma**	**Co–morbidities**	**Receiving benefits or care**
Joyce (56F)	Married with supportive partner	Relief that it was "real". Some engagement with psychological explanations	They are "real" but they are linked to trauma and suffering	Yes- multiple and including CSA*	Fibromyalgia, chronic pain, gut and brain surgeries in past	Sickness and incapacity benefits. Cared for by her husband.
Chrissie (64F)	Married with supportive partner	Shock and confusion at the unsought diagnosis. Negative effect of losing driving license	Thought she had fainting fits	Not identified by self but emerging in interview	Arthritis, cardiovascular disease.	Sickness benefits. Cared for by her husband.
Sally (53F)	Has always lived in the family home. Father died recently and mother has dementia	Convinced that there were other things wrong. Angry at not being taken seriously.	Long history of poor health and multiple interventions but always in full-time work	Childhood was wonderful- no trauma. Extensive childhood use of medical services	Multiple surgeries for joint and nerve problems	In the process of being medically retired from work. Engaged in arguments about the nature of her illness and entitlement to retirement.
Natalie (34F)	Engaged to be married to supportive fiancé	Shock, shame and embarrassment. Didn't feel a stress-based explanation fitted with her life	All seizures had been in relation to surgery or infection. Assumed they were organic in nature.	Participant felt strongly that she had no traumas. Extensive childhood use of medical services	Chest and throat infection, minor surgery on wrist. Very fit as she is a sports teacher.	In full time work. No care provided but very supportive fiancé and parents.
Maxine (43F)	Widowed with two teenage children. Husband died of alcohol related disease	Shame and embarrassment and some disbelief and confusion (especially as she was still being prescribed anti-epilepsy drugs).	Had had provisional diagnoses of stroke, migraine and epilepsy	Loss of husband but Maxine had not seen this as possibly relevant until explored in the interview	Depression	Benefits and trapped in a low paid job that she dares not leave for financial reasons. Receives some care from adolescent children.

*CSA: Child sexual abuse.

3.2. Findings

Analysis identified five themes related to legitimacy and medicalization. These were: the plausibility of stress-based explanations (including how participants described their condition to others); the place of feelings; an unsought diagnosis; explanations that help; and medical ambivalence around medicalizing. This latter category leads us into a wider discussion of the meanings of the findings.

3.2.1. Theme 1. The plausibility of psychological/ stress-based explanations

Participant name	**Extract number**	**Extract**
Joyce	1.1	*“I don’t know. It’s like I said to you, all this stress of this news of my brother dying and yet I haven’t had a load of seizures. So, I kept thinking: Is it stress? But…You can’t put everything down to stress, can you?”*
	1.2	*“Nobody ever asks me Is there anything going on at the moment that’s upsetting you in your life that could be bringing this on?”’ You know? Or ‘What do your think’s caused it this time?’ You know. ‘I know you’re busy, I know you’re short of staff, I’m not gonna take all your day up.”*
	1.3	*“But they seem to think, ‘Oh, her brother got killed, that’s why she’s back in with seizures.’ No, it’s nothing to do with that. I started long before that”.*
Chrissie	2.1	*“I just put that down to, I don’t know, everyday life. If you’ve got stressed over……a bill or…, you know. And I just… so I’d sort of related it to that type of thing, you know… I related that to that type of… day-to-day stresses……sort of thing. Nothing beyond that”.*
	2.2	*“She* [diagnosing doctor] *was the one that said had I ever been abused as a child; had I been mugged and everything else. And I sort of went… ‘What? My dad? No. Flippin’ heck. You say boo to my dad he’d have run a mile.”*
Sally	3.1	*“That bothers me because there are unsympathetic people, there are people that put two and two together and make 600”.*
Natalie	4.1	*“I had the perfect upbringing. I mean my family’s not well-off, but they’ve always been comfortable. I’ve never gone without and always been on holidays and anything at school needed… Mum and dad have got a perfect relationship”*
	4.2	*“To be honest, it makes me feel like a hypochondriac because I think … they’re just telling me it’s psychological and this is why it’s happening and it’s… psychological doesn’t really… well, it probably is in terms, but to me it’s not, it’s just like it’s happening because you’re stressed. And I’m thinking I’m not… I’m not stressed. But, yeah, there is kind of… I am… it does worry me but not in the sense that like, if it is psychological, I’d like to know what it is so I can obviously deal with that, so it doesn’t happen again.”* *”I’ve been more stressed since being diagnosed with this than I was before.“*

Consonant with other studies [23,24], our participants reported a lack of fit when psychological, psychosocial, or stress-based explanations are offered for NEAD. The condition “feels” physical, as seizures and collapse are usually understood in this way. Psychological explanations, therefore, often came as a shock. Participants thought they had epilepsy, and the first time a psychological explanation was suggested was when organic disease had been excluded.

For Joyce, uncertainty is evident as she struggles with making sense of the explanations offered (Extract 1.1). In the case of Chrissie, the implausibility of psychological explanations connects with her understanding of what “stress” is (2.1) and her shock about being asked in the diagnostic interview if her father had sexually abused her (a reaction shared with Sally and Natalie; 2.2).

Some participants found psychological explanations untenable. Natalie had looked up information on NEAD online prior to her diagnosis, and already determined she did not consider it appropriate; she felt that her upbringing had been *“perfect*”, excluding the possibility of NEAD (4.1). She experienced stress as a consequence, not cause, of her seizures – both of the seizures themselves and subsequent healthcare interactions (4.2).

Others shifted between resistance to psychological explanations and (albeit cautious) engagement with them. Some participants simultaneously resisted unwanted stress-based explanations while identifying a lack of interest from medical professionals in contemporary life events they thought relevant (Joyce, 1.2–3; similarly for Sally, who initially links her seizures to her father’s recent death, but on further exploration says that the seizures pre-date this and connect them instead with her experiences of surgery). These ambivalences display interactional resistance [5] to psychological explanations while simultaneously offering “knowledgeable narratives” [25]; internally coherent reflections of how participants make sense of their experiences.

All participants were sensitive to the social consequences of a psychological explanation for illness with some (e.g., Sally (3.1)) anticipating the responses of others to the diagnosis. Such explanations are often perceived as stigmatizing, viewed as a sign of madness or weakness, or as malingering, and do not provide a gateway to legitimate illness in the way that “organic” or biomedical explanations do. Furthermore, as Salmon and Hall [26] (p. 1973) have commented, such explanations *“locate responsibility with patients by constructing them as active agents managing their disease,*” and emphasis is placed on a faulty or malfunctioning response to stressors by the individual rather than on the stressors (or the traumas) themselves.

3.2.2. How participants described their condition

Participant name	Extract number	Extract
Sally	3.2	*"I went to see another neurologist and he was totally disinterested... absolutely dismissive, totally uninterested, and I felt like I was wasting his time. And I just exploded, and I just said, 'I'm so unhappy with (this hospital) ..., 'You're the third person I've seen: the doctor who told me these won't happen again. I don't want to hear that.' And I said, 'I just need to know what they are and if you can help me.' And he just said, 'I tell you what,' he said, 'there are people like you out there.' he said, 'Seen a few, met a few, but, you know, it's nothing serious, there's nothing to worry about.' He said, 'It's not epilepsy – be thankful for that.'"*
Maxine	5.1	*"I just say... I just tell'em it's like epilepsy...but it isn't epilepsy. But then you have to start saying like... but they don't know what it is, do you know what I mean? So, I just say it's epilepsy......because nobody knows what it is, do they? So, it's a lot easier to just say it's epilepsy." [When this is explored further, she goes on to say] "I've been to see (Dr H) for about t'last two and a half, three years and I've had all them EEGs and MRIs and whatever and he said he didn't know whether it was migraine-based and he didn't know whether it were epilepsy. And then they've had this... what is it?* Interviewer; "*Non-epileptic attacks?*" *"Attacks, yeah, but nobody's actually said, 'Yeah, it is that.' Nobody's actually said, 'Yes, it is that.' So, nothing's actually been diagnosed, that's why they've said it must be... This....non-epileptic attack, right*".

The most common explanation that participants gave to others was that it was epilepsy, or something like epilepsy, as this resulted in less embarrassment and exposure (extract 5.1). When this explanation is medically rejected, frustration or anger results from the lack of an acceptable diagnosis and subsequent illness trajectory (3.2).

Both Natalie and Sally felt NEAD failed to explain their symptoms and worried that a functional diagnosis disqualified them from further "organic" investigation. Struggling to fit explanations offered with their experience caused discomfort and frustration.

3.2.3. Theme 2. The place of feelings and the constraints of context

Participant name	Extract number	Extract
Maxine	5.2	*"I was at work I was working behind t'tills and all my face started dropping and my hand like went into a claw*".
	5.3	*"It's monotonous... it's... you're just there, you're just... it's like being on a conveyor belt and you're just there... just... monotonous really and... it's a means to an end, but at t'end of t'day it's...it's not me basically.*"
	5.4	*"I daren't go back, but I daren't pack it in...And I daren't go forward for another job until I can say... 'I used to have these fits but I haven't had one for ages.*" *"I think that's... that's t'top and bottom of it: if I could get... or if I could get a new... new challenge, new focus, new... summat to set my mind on really. So... I think that's t'way forward really. And summat to use my brain on really. Just... not working in silly (Store), although it pays t'bills.*"
	5.5	*"it does make sense, and I don't know if it makes any difference, but when we were going home on t'bus last time, me and my mum... think my dad suffers like this. Because, when my dad worries a lot, his... his stomach plays up. He used to come out in a lot of psoriasis, he used to have psoriasis, and he once come out in psoriasis when he got threatened with redundancy at work and... but then, as soon as his job were all right, it completely went. But, do you know..., things like that, it's... it's on t'same thing but it's a different... how it comes out in a different way. And me and my mum were talking like that and it's like mine's like manifested it in a different way*".

There is further difficulty with psychological and stress-based explanations, with a range of studies [5] showing that many of those diagnosed with NEAD find it hard to access or locate their own feelings. Maxine struggles with an "unspeakable dilemma" [27] a significant life difficulty that cannot be acknowledged or thought about. She works at a job (large-volume clothing retailer) that she hates but cannot leave for financial reasons. Some years prior to the interview, Maxine was forced to resign from her much-valued job in a bank to care for her children and husband, who eventually died in his 40 s from chronic alcohol use. She describes feeling trapped in a job that does not fit her identity (5.3) but that she cannot leave (5.4). A period of sick leave has served to deepen her frustration.

Maxine identifies that she is from a family that does not speak of feelings and is surprised to be asked by the interviewer if she connects her husband's death to her seizures. They explore this a little, and then in a second interview (5.5), Maxine reflects on this via the recollection of a conversation with her mother. This highlights her capacity to reflect and consider new perspectives.

Maxine's testimony also demonstrates the recursive relationship between contested diagnoses like NEAD and the contemporary labor market and social security system. We explore this relationship further in the discussion.

3.2.4. Theme 3. An unsought diagnosis

Participant name	**Extract number**	**Extract**
Chrissie	2.3	"I *used to have one or two, but I think they just put them down... they were faints, you know.... And they said, 'Oh, you'll grow out of'em,'*".
	2.4	"*So, I'd had all these tests done and then ... because I'd moved out of the area, we had to change doctors. I did explain to the doctors roughly what was wrong with me so that they didn't have to repeat anything... because I thought it would be a waste of money*".

Although many people seek a "medical" explanation, this is not always the case. Chrissie had experienced "blackouts" or "fainting fits" since being a young woman and did not actively seek a biomedical explanation (extract 2.3). This diagnosis had not served to limit activities or label her in any way pejoratively, and no explanation was required or offered to her. Any distress or suffering associated with the blackouts was bearable; she felt no need to interrogate the symptoms' significance (a prerequisite of a psychological approach). It was only when NHS processes triggered routine investigations, unsought by Chrissie, that her experiences became medicalized (2.4).

Chrissie cautiously resisted further investigations but felt that this reluctance was interpreted as resistance to "psychological" explanations of NEAD. For her, medicalization of long-standing life experiences produced a diagnosis that was embarrassing (with links to adverse life experiences, particularly the suggestion that she may have been sexually abused in childhood) and practically limiting (as she was unable to drive due to the "seizures").

While most participants sought a definitive label for their experiences (3.2), Chrissie's account demonstrates that some find ambiguity prior to further investigations untroubling [28].

3.2.5. Theme 4. Explanations that help

Participant name	**Extract number**	**Extract**
Joyce	1.4	*And (*the professor*) wrote me a letter ... So, I took it into hospital and I give it'em and I said... and the Professor wrote: 'This lady does not do this at will. These are real... this is a real illness.' And I thought: Wow, thank you, Prof... you know. And I give it'em and said, 'Will you please put that in my records.'* *"And then anyway ..., I had a (*Dr T*) come to me and she said to me, the Consultant, 'It's about time you started helping yourself.' I said, 'Excuse me, (*Dr T*) ...' she was a lot younger than me... I said, 'I go out every day. I live my life as normal as possible. I'm a people's person.' And she said, 'Well, it's about time you started helping yourself.'*
	1.5	*"First, it's got a name......secondly* ***that it's real*** *...but of course that it can go as quick as it came. That's all you need to hear. And when it comes from someone who knows what they're talking about, (*chuckling*) that's even better*". (Emphasis added).
Chrissie	2.5	*"I suppose in one sense it was a relief to know that somebody else who dealt in that field said what it was, what it actually was. That was a bit of relief, although sort of we'd been told that prior, but to hear it off somebody who actually deals with fits and everything like that. So that was quite nice to listen to. Well, I don't... I suppose if they had had been fits, I suppose I might have been lucky because I could have probably had medication in that respect*".

Participants found explanations satisfactory when, firstly, delivered by an expert (epistemic recourse to authority) such as a psychologist or a clinician but ideally by a neurologist (one of the neurologists in our study team figured in this way in several of the accounts), and secondly, they made clear that the condition was "real". Such explanations legitimize illness experiences and can be used by those who have received them in other contexts (extract 1.4). However, while such explanations may prove practically helpful, they can also unsettle by raising questions of treatment (2.5).

3.2.6. Theme 5. Medical ambivalence about medicalizing

Participant name	Extract number	Extract
Chrissie	2.6	"(Dr B) *said it's not epilepsy.' And when I said I wouldn't go on the tablets . . . I said, 'Well, I don't want to go on taking something if I haven't got it*".
Maxine	5.6	*"At first they were right good but like. . . they put me on a little dose and then like, as I got used to that dose, and then. . . and I had to up it and up it and up it. And it was like I'd get used to t'dose and I'd start having t'fits again, but then when it was due for me upping I'd up it like every three months, I think it were*".

It is not just participants who medicalize and have an ambivalent relationship with explanations for NEAD. The apparent ambivalence of clinicians, including neurologists, about NEAD etiology, pathophysiology, and treatment deepened uncertainty. The prescribing of anti-seizure medications (Extracts 2.6, 5.6) was experienced as inconsistent with the lack of a biomedical explanation for the seizures. Similarly, Joyce was given contradictory messages when her GP called an ambulance to the surgery because she had started to have a seizure there. This was considered to have gone on for "*too long*", thus posing a risk to her physical health.

4. Discussion

Early sociological work establishing the concept of medicalization (alongside associated concepts, e.g., overdiagnosis or treatment) critiqued its transformation of suffering or of particular characteristics of people or groups into the domain of medicine [29,30]. More recent work has avoided exclusive focus on *over*medicalization and explored diagnosis as a social process and '*an enabling factor of medicalization*' [31,p.9].

Medical diagnoses confer legitimacy to patients and become an interactional resource for presenting one's (sick) self to others [32]. With NEAD, like many other functional or contested diagnoses, we find that "non-organic" explanations for seizures undermine successful assignment of the sick role and the ability convincingly to account for an 'ill' self [33]. Clinicians may strive to set boundaries for conditions that are difficult to manage within contemporary biomedicine [26]. Patients, in response, may actively seek medical legitimacy and resist or disavow "demedicalization" or "psychologization" as alternatives to a biomedical explanation of their symptoms.

The challenges of maintaining a legitimate patient identity with a NEAD diagnosis become very stark when comparing this condition with epilepsy [34]. Many people with NEAD are so incapacitated by their condition that they are unable to work [5,6]. While all patients with variable symptoms may be poorly understood and treated by the contemporary UK benefits system, a person with epilepsy can claim that they do not let their condition interfere with their life or the range of things they can do, yet still legitimately occupy a sick role. A person with NEAD who does the same will undermine their claim to the NEAD label because, without abnormalities in functioning, there is no residual sick role category. The NEAD name for a set of symptoms is essentially descriptive. Thus, those living with a diagnosis of NEAD are often caught in a bind of desiring to be well but dependent on symptoms for access to the societally sanctioned status of a sick person and entitlement to associated social security support (benefits). While the conditionality built into the contemporary neoliberal benefits system can only account for a part of the struggles of those with NEAD, this imperative to medicalize suffering increases as other routes to legitimacy are closed.

The consequent embrace of medicalization contrasts with social movements, which aim to locate suffering and symptoms in their social, cultural, and political contexts. Szasz famously proposed that the difficulties and suffering experienced by people were not "illness" or "disease" but "*problems in living*" [35]. Others have commented on how neoliberalism shapes discourses of responsibility, stigma, and blame in the sphere of welfare politics and also in the broad domain of health and illness [36]. In the context of long-term mental distress, Greener and Moth [37] interrogate what they refer to as neoliberal social policy reforms, which recast mental distress as an internalized, moral category. What neoliberalism does, they argue, is to present suffering as a personal failure with interventions designed to promote personal resilience while remaining silent around structural features such as poverty or discrimination that might shape that suffering [38].

This contrast may explain the ambivalence towards medical framings of NEAD seen in our study. Participants identified the contemporary social requirement for a medical diagnosis for NEAD and sought this for themselves, but there was also some recognition that this process of medicalizing then serves to exclude and disavow suffering that has not been medically legitimized. While the label did not always accord with their experience, our participants were able to use it to serve desired social ends, leaving them "bargainers" with the medicalization of their experience [39].

The NEAD also helps illuminate the mechanisms of medicalization. The work of Nettleton [16], and others [40] indicates the reinforcing relationship between diagnosis and medical technology, emphasizing how the latter serves to delineate the "organic" (medicalized) from the "non-organic". While space does not permit a detailed discussion of the organic/functional divide in medicine, in the case of NEAD, this debate has evolved from one of the mere presence or absence of demonstrable pathophysiological changes to one about the clinical significance of subtle changes observed with highly sensitive modern imaging techniques such as fMRI or brain tractography at the group rather than individual patient level. The salient questions now are whether these changes are sufficient to explain the disorder's manifestations and whether they are the cause, consequence, or merely an association of the clinical manifestations.

The increasing application of the technological gaze to NEAD will maintain it within the purview of medicine (and this is almost certainly what patients would expect and require). However, we argue that including the "*problems of living*" and the nature and place of suffering would deepen the understanding of NEAD amongst clinicians and patients. For instance, integrating social factors into a clinical formulation might improve treatment as well as aid and improve communication between clinicians and patients around the condition. In addition, extending social, political, and demographic knowledge via research around NEAD could serve to both extend and develop current concepts of the condition.

5. Conclusion

In the context of contemporary neoliberalism, medicalization serves to legitimize suffering and gatekeep access to contemporary benefit systems. The persistence of the simplistic division between the "organic" (real) and the psychological, and the implicit hierarchy of legitimacy placing the former above the latter, can complicate patient acceptance of "non-organic" diagnoses [41]. Cartesian dualism has arguably made much medical progress possible [26], but it also serves to divide and hold us back in ways that frequently impede or limit understanding.

Connections between the individual body and their social context have always existed and have always shaped illness experience. NEAD and similar conditions highlight the difficulties in trying to view such experiences through both lenses simultaneously. The imperative to shoulder personal and individual responsibility for health, alongside a disavowal of the social, a focus on othering, and a dismissal of suffering, all add to the burden of living with NEAD [42–45]. For clinicians, recognizing the social circumstances in which the condition is embedded, not simply as contextual information but as intrinsic to the illness process, may help to make better sense of symptoms in dialogue with patients. Doing so may help clinicians engage with the "interactional resistance" so commonly identified in consultations with people with NEAD [23]. Understanding and focusing on the legitimacy being sought by patients and what might underpin this could find new and more productive ground for dialogue.

Beyond supporting patients to engage with the relevant psychosocial context for their condition, clinicians may help their struggle for legitimacy in a two-pronged fashion. On the one hand, they can support their patients in navigating the social implications of their diagnosis by using their epistemic authority to legitimize patients' symptomatic complaints. The clinician authors of this paper will regularly write "to whom it may concern" letters that patients may use to explain their condition to others. With the patient's consent, they may also arrange meetings with schools, employers, or colleagues of patients with NEAD, explaining the diagnosis, how it may affect their social functioning, and what reasonable accommodations may be of use. By doing so, we are able to use medicalization in its strictest sense—identifying a human phenomenon and asserting that it falls within the scope of medical definition and practice—to legitimize their experience, but also empower patients to continue to maintain a valued non-sick identity (e.g., by asserting that non-epileptic seizures should not pose unacceptable risks to their continuing to hold a particular working role—if necessary with "reasonable adjustments" as directed by UK disability legislation).

On the other hand, they can simultaneously acknowledge their patient's suffering and be explicit about the limitations of the medical lens in articulating all that is important about people's lives and experiences. We have elsewhere suggested that clinicians should cultivate an attitude of 'epistemic humility' towards the role and scope of medical descriptions of human phenomena [46]. This involves both an awareness of the limitations of the conceptual resources of medicine to describe all that is important in people's lives and a commitment to seek complementary perspectives that may overcome these limitations. The way participants relate their illness to their social world may differ from that of their clinicians (as in section 3.2.1 above), and clinicians can acknowledge this by complementing their medical description with the patient's illness experience. Co-creating illness formulations, as used in psychiatric and psychotherapeutic practice, can be one tool to operationalize this in the clinic; online tools are also now available to allow patients to explore this independently.

Together, these approaches may support people with NEAD in navigating a social landscape in which medicine holds a monopoly on legitimate suffering while simultaneously trying to break that monopoly and help them identify non-medicalized solutions to their "problems in living."

Funding

This study was funded by a grant from the Ryder Briggs Foundation.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

References

[1] Hingray C, El-Hage W, Duncan R, Gigineishvili D, Kanemoto K, LaFrance Jr WC, et al. Access to diagnostic and therapeutic facilities for psychogenic nonepileptic seizures: an international survey by the ILAE PNES Task Force. Epilepsia 2018;59(1):203–14. https://doi.org/10.1111/epi.13952.

[2] Stone J, Carson A, Duncan R, Roberts R, Warlow C, Hibberd C, et al. Who is referred to neurology clinics?-the diagnoses made in 3781 new patients. Clin Neurol Neurosurgery 2010;112(9):747–51.

[3] Jennum P, Ibsen R, Kjellberg J. Morbidity and mortality of nonepileptic seizures (NES): a controlled national study. Epilepsy Behav 2019;96:229–33.

[4] Dickinson P, Looper KJ, Groleau D. Patients diagnosed with non-epileptic seizures: their perspectives and experiences. Epilepsy Behav 2011;20(3):454–61.

[5] Brown RJ, Reuber M. Psychological and psychiatric aspects of psychogenic non-epileptic seizures (PNES): a systematic review. Clin Psychol Rev 2016;45:157–82.

[6] Tan M, Pearce N, Tobias A, Cook MJ, D'Souza WJ. Influence of comorbidity on mortality in patients with epilepsy and psychogenic nonepileptic seizures. Epilepsia 2023;64(4):1035–45.

[7] Reuber M, Baker GA, Gill R, Smith DF, Chadwick D. Failure to recognize psychogenic nonepileptic seizures may cause death. Neurology 2004;62(5):834–5.

[8] Whitehead K, Kandler R, Reuber M. Patients' and neurologists' perception of epilepsy and psychogenic nonepileptic seizures. Epilepsia 2013;54(4):708–17.

[9] Coebergh JA, Damian RW, Colin JM. "Undiagnosing" neurological disease: how to do it, and when not to. Pract Neurol 2014;14(6):436–9. https://doi.org/10.1136/practneurol-2013-000796.

[10] Brown RJ, Reuber M. Towards an integrative theory of psychogenic non-epileptic seizures (PNES). Clin Psychol Rev 2016;47:55–70. https://doi.org/10.1016/j.cpr.2016.06.003.

[11] Myers L, Trobliger R, Bortnik K, Lancman M. Are there gender differences in those diagnosed with psychogenic nonepileptic seizures? Epilepsy Behav 2018;78:161–5.

[12] Jones LL, Rickards H. History of abuse and psychogenic nonepileptic seizures: a systematic review. Seizure 2021 Nov;92:200–4.

[13] Goldstein LH, Robinson EJ, Mellers JD, Stone J, Carson A, Chalder T, et al. Psychological and demographic characteristics of 368 patients with dissociative seizures: data from the CODES cohort. Psychol Med 2021;51(14):2433–45.

[14] Van Campen JS, Jansen FE, De Graan PN, Braun KP, Joels M. Early life stress in epilepsy: a seizure precipitant and risk factor for epileptogenesis. Epilepsy Behav 2014;38:160–71.

[15] Ludwig L, Pasman JA, Nicholson T, Aybek S, David AS, Tuck S, et al. Stressful life events and maltreatment in conversion (functional neurological) disorder: systematic review and meta-analysis of case-control studies. Lancet Psychiatry 2018;5(4):307–20.

[16] Nettleton S. 'I just want permission to be ill': towards a sociology of medically unexplained symptoms. Soc Sci Med 2006;62(5):1167–78.

[17] Parsons T. Illness and the role of the physician: a sociological perspective. Am J Orthopsychiatry 1951;21(3):452.

[18] Hollway W, Jefferson T. Doing qualitative research differently: a psychosocial approach. 2nd ed. London: SAGE; 2013.

[19] Peacock M, Dickson JM, Bissell P, Grunewald R, Reuber M. Beyond the medical encounter: can the free association narrative interview method extend psychosocial understandings of non-epileptic attack disorder? J Psychosoc Stud 2022;15(1):36–51.

[20] LaFrance WC, Gus AB, Rod D, Laura HG, Markus R. Minimum requirements for the diagnosis of psychogenic nonepileptic seizures: a staged approach: a report from the international league against epilepsy nonepileptic seizures task force. Epilepsia 2013;54(11):2005–18. https://doi.org/10.1111/epi.12356.

[21] Jovchelovitch S, Bauer MW. Narrative interviewing. Qualitative researching with text, image and sound. 2000;57:74

[22] Frank AW. The wounded storyteller: body. Illness Ethics 1995;3:3.

[23] Monzoni CM, Duncan R, Grunewald R, Reuber M. Are there interactional reasons why doctors may find it hard to tell patients that their physical symptoms may have emotional causes? A conversation analytic study in neurology outpatients. Patient Educ Couns 2011;85(3):e189–200. doi: S0738-3991(11)00381-8 [pii]10.1016/j.pec.2011.07.014.

[24] Monzoni C, Duncan R, Grunewald R, Reuber M. (2011) How do neurologists talk about medically unexplained symptoms? A conversation analytic study. J Psychosom Res 2011;71(6):377–83.

[25] Williams GH. Knowledgeable narratives. Anthropol Med 2000;7(1):135–40.

[26] Salmon P, Hall GM. Patient empowerment and control: a psychological discourse in the service of medicine. Soc Sci Med 2003;57(10):1969–80.

[27] Griffith JL, Polles A, Griffith ME. Pseudoseizures, families, and unspeakable dilemmas. Psychosomatics 1998;39(2):144–53.

[28] Harper DJ. De-medicalising public mental health with the Power Threat Meaning Framework. Perspect Public Health 2023;143(3):151–5.

[29] Conrad P. Medicalization: Changing contours, characteristics, and contexts. In: Cockerham WC, editor. *Medical Sociology of the Move*: *New Directions in Theory*. London: Springer; 2013.

[30] Joseph D. Medicalisation, social control, and the release of suffering. Blackwell companion to medical sociology; 2010.

[31] Jutel A. Putting a name to it: diagnosis in contemporary society. Maryland: John Hopkins; 2011.

[32] Wardrope A, Reuber M. The hermeneutics of symptoms. Med Health Care Phil 2022;25(3):395–412.

[33] Risør MB. The process of symptomatization: clinical encounters with functional disorders. In: Fainzang S, Haxaire C, editors. Of bodies and symptoms: anthropological perspectives on their social and medical treatment. Tarragona: Publicacions Universitat Rovira i Virgili; 2011.

[34] Jennum P, Ibsen R, Kjellberg J. Welfare consequences for people diagnosed with nonepileptic seizures: a matched nationwide study in Denmark. Epilepsy Behav 2019;98:59–65.

[35] Szasz TS. The myth of mental illness: foundations of a theory of personal conduct. Secker & Warburg; 1962.

[36] Wilson K. Neoliberalism. London: Routledge; 2018.

[37] Greener J, Moth R. From shame to blame: institutionalising oppression through moralisation of mental distress in austerity England. Soc Theory Health 2020. https://doi.org/10.1057/s41285-020-00148-8.

[38] Peacock M, Bissell P, Owen J. Dependency denied: health inequalities in the neoliberal era. Soc Sci Med 2014;118:173–80. https://doi.org/10.1016/j.socscimed.2014.08.006 [published online ahead of print, August 2014].

[39] Dumit J. Illnesses you have to fight to get: facts as forces un uncertain emergent illnesses. Soc Sci Med 2006;62:577–90.

[40] Fainzang S. The other side of medicalization: self-medicalization and self-medication. Cult Med Psychiatry 2013. https://doi.org/10.1007/s11013-013-9330-2.

[41] Bell V, Wilkinson S, Greco M, Hendrie C, Mills B, Deeley Q. What is the functional/organic distinction actually doing in psychiatry and neurology? Wellcome Open Res 2020;5.

[42] Robson C, Lian OS. " Blaming, shaming, humiliation": stigmatising medical interactions among people with non-epileptic seizures. Wellcome Open Res 2017;24(2):55. https://doi.org/10.12688/wellcomeopenres.12133.2 [PMID: 29152594; PMCID: PMC5664997].

[43] Bourdieu P et al. The Weight of the World: Social Suffering in Contemporary So), trans. Priscilla Parkhurst Ferguson et al. Stanford University Press; 1999.

[44] Goldstein LH, Robinson EJ, Mellers JD, Stone J, et al. Psychological and demographic characteristics of 368 patients with dissociative seizures: data from the CODES cohort. Psychol Med 2021;51(14):2433–45.

[45] Goleva SB, Lake AM, Torstenson ES, Haas KF, et al. Epidemiology of functional seizures among adults treated at a university hospital. JAMA Netw Open 2020;3(12):e2027920–e.

[46] Wardrope A. Medicalization and epistemic injustice. Med Health Care Philos 2015;18(3):341–52. https://doi.org/10.1007/s11019-014-9608-3.

Glossary of sociological terms

Liminal/liminality: The transitional period from one social role to another, characterized by fluidity and uncertainty in status and responsibilities.

Responsibilization: The shift of risk or responsibility for managing a given problem away from governments, institutions, or other collectives, and onto the individual

Neoliberalism: A form of capitalist political economy characterized by financial deregulation, privatization, reduced public spending, and an emphasis on free markets over state intervention.

Othering: A process by which members of certain groups (e.g., by visible physical difference, national or ethnic origin, or citizenship status) are identified as relevantly different from a majority or politically dominant group. Usually employed to denote the 'othered' group as of inferior status, to legitimize discriminatory treatment.

Medicalization: The process by which experiences, behaviors, or other phenomena become subject to definition by medical institutions and managed by medical practitioners.

Sick role: A change in social rights and responsibilities sanctioned by sickness; disease diagnosis gatekeeps legitimate access to this role.