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Non-epileptic attack disorder (NEAD): trauma and life events, context and meaning

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ABSTRACT

This paper makes the case for a re-consideration of the role of trauma and life events – and crucially, their social and political context – in relation to non-epileptic attack disorder (NEAD). Trauma and adverse life events have well established links with many health conditions and whilst they are acknowledged to play a part in NEAD, more recent research suggests that such events are not ubiquitous. Currently, when events are seen as salient this is most commonly interpreted in relation to properties of the individual and their agency. Context – social and political factors – are seldom integrated or considered.

This paper presents findings from a study which examined how trauma and life events were understood by participants, how frequently trauma and life events were present in participants' accounts and in what ways they may be salient as predisposing, precipitating or perpetuating factors in NEAD. Employing a validated a life history questionnaire to purposively sample participants with high and low levels of self-reported trauma, we deployed a narrative interview approach which elicited rich descriptions of life experiences.

We found that descriptions of trauma or adverse life events were present in all our participants and that these events were shaped by social contexts of their lives. We propose that the method used to collect trauma data is central to what is found and that a recognition of the social and political context, and their meanings, results in a more nuanced understanding of the place of trauma and life events.

“Listen to your patient, [s]he is trying to tell you the diagnosis” William Osler.

1. Introduction

Trauma and adverse life events (ALEs), and, in the case of the latter, those considered to be serious or significant (SSLEs), have well established links with a wide range of both physical and mental health conditions including non-epileptic attack disorder (NEAD), the focus of this paper. SSLEs are events which feature marked threat, loss, danger and humiliation. (Bifulco et al., 2020). The seizures which characterise this

disorder are also known as psychogenic, dissociative or pseudoseizures (the latter terminology being widely disliked). Termed functional or dissociative seizures in recent nosologies (DSM-5, ICD-11), for the purpose of this paper, we are using NEAD; the name for the disorder most commonly used by the participants in our research. Trauma and adverse life events have been considered salient as precipitants to illness onset, as part of the mechanisms underpinning the maintenance and duration of illness or as potential ‘sensitising’ factors, opening doors to other mechanisms that might explain the patterns of pathology that subsequently emerge. These processes are usually understood using a bi-psychological lens, focusing on such issues as relational and attachment styles, coping skills, and the biological effects of trauma such as chronic

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arousal, activation of the immune system and co-morbidities such as depression, anxiety or certain personality traits (Beghi et al., 2020; Jones & Rickards, 2021).

What is missing in this formulation, is context and meaning and the social and political landscapes which shape trauma, all of which are underdeveloped and under-theorised in contemporary clinical settings. This is despite evidence that this absence de-contextualises, depletes and deracinates understandings of trauma. As Greenhalgh (2016, p. 8) proposes, commenting on the mental health problems often experienced by refugees, “*a shared past experience of separation, loss, physical hardship, discrimination, poverty, and persecution ... may be crucially important influences upon the nature and course of the illness*”. Without understanding and incorporating social, cultural and political experiences, the place of trauma in illness and its consequences are obscured, distorted or lost. This leaves a gap which, may be filled by the medicalisation of suffering and illness, where factors such as gender, inequality, epistemic injustices and structural violence are disavowed, trivialised or marginalised. It may also close off the possibility of recovery from trauma through psychological therapies which take into account the importance of narrative and meaning.

The prevalence and nature of trauma (and ALEs) in NEAD is a particularly salient consideration in both patient and clinical discourses in light of the removal of trauma as an essential diagnostic criterion of Functional Neurological Symptom (Conversion) Disorder (FND) in the DSM-5 and in the context of contemporary debates concerning the place of ALEs and social factors in FND. (Reuber, 2018; Ludwig et al., 2018). When establishing the presence/absence of trauma, in clinical settings and as understood in wider discourses, we propose that what is reported is a product of the wider contemporary social and political consensus concerning what constitutes trauma, the methods used to explore this in clinical settings, and the ontological and epistemological positions of those seeking the information. The ambiguous and socially constructed nature of trauma is seldom fully acknowledged. Collecting trauma data is not neutral for data gatherers nor information providers, with both having conscious and unconscious investments in what constitutes the category “trauma”, in what is investigated and how. As Morsy et al. (2021) note, “*the more thorough the search, the more trauma is identified*” (P 261).

To address these questions, this paper reports the main findings of a study seeking to answer the question “*Can the relevance of ‘trauma’ and life events in the aetiology and maintenance of non-epileptic attack disorder (NEAD) be better understood by the use of the Free Association Interview (FANI) method?*” As the quote from Osler (above) indicates, the use of a narrative approach was central to our methodological choice. In a previous study, we found that trauma could be disavowed or not seen as trauma by participants, and that the method used to explore experience was central to the narratives which emerged and thus to more accurately understanding trauma prevalence and the meanings of such experiences (Peacock et al., 2022). With this larger study we again utilised the FANI method alongside a validated trauma scale capturing patients’ experiences in childhood, adolescence and adulthood (Lifespan Negative Experiences Scale- LiNES- see online supplementary file for more information) to purposively sample participants with self-reportedly high or low levels of trauma for interview in order to arrive at the conclusions reported.

2. Background

2.1. NEAD-a short introduction

NEAD has an estimated prevalence of 30–50 per 100,000 people, around three quarters of whom are women (Myers et al., 2018), and is frequently encountered in neurological services where approximately 20 % of patients newly presenting to epilepsy clinics receive the diagnosis (Stone et al., 2010; Villagrán, & Eld-øenDuncanAbergHofossLossius, 2021) Non-epileptic seizures are

embodied events that can resemble epilepsy and are “functional” in that they are not underpinned by the pathophysiological changes which characterise epilepsy or other causes of transient loss of consciousness such as syncope (Vijay & Reuber, 2024). It is well established that more patients with NEAD than with epilepsy (Jones & Rickards, 2021) or members of the general population (Goleva, 2020; Beghi et al., 2020), report histories of trauma, neglect and abuse including sexual abuse.

NEAD represents a considerable illness burden with many people with the disorder (and those who care for them) being unable to work or experiencing restrictions in many aspects of life (Jennum et al., 2019). There are higher rates of deaths, including suicide, in those with NEAD than in age-matched general population controls, which may well reflect the high rates of disadvantage and abuse amongst those with NEAD and the associated embodied health risks (Duncan et al., 2012; Faiman et al., 2022; Goldstein et al., 2019). Of those eventually diagnosed with NEAD many are initially thought to have epilepsy, which can lead to exposure to serious risks from unnecessary medical treatments, as well as missed opportunities to understand and engage with the nature of the seizures (Reuber et al., 2004).

The diagnostic process can be experienced as difficult, contested and stigmatising-a place where both clinicians and patients frequently struggle, especially when the diagnosis has to be changed from an “organic” explanation (like epilepsy) to a condition currently categorised as a mental health disorder (Thompson et al., 2009). This lack of “organicity” can also undermine feelings of legitimacy and the “*claims to exemption*” central to the “*sick role*” (Reuber et al., 2004). Stress based or “psychological” explanations for symptoms are usually provided in clinical consultations and these may be difficult for patients to integrate and make sense of, leading to dissatisfaction and discursive tension (Monzoni et al., 2011).

2.2. Trauma and life events; the salience of context

Whilst rates of trauma and SLEs are high there is uncertainty as to how high and to what extent and in what ways external, “social” factors are salient amongst those with NEAD. Ludwig et al. (2018), in a systematic review looking at functional neurological disorders more widely, including patients without dissociative seizures, identified that whilst trauma was reported over eight times more frequently than in healthy controls and around twice as frequently than among neurological or psychiatric controls, “*many cases report no stressors*” (Ludwig et al., 2018, p. 307). The findings of their meta-analysis reflected the ways in which trauma data has most frequently been collected by using self-report questionnaires or clinical interviews. Questionnaire studies identified lower trauma rates than those involving clinical interviews. However, it was papers utilising detailed interviews based on the Life Events and Difficulties (LEDS) scale which identified the highest rates including a study by Nicholson et al., (2016 p 2624) where the authors found, “*LEDS identified four times more stressors ... than clinical interviews*”. LEDS is a structured, in-depth approach that incorporates, importantly, the contextual meaning of the events as well as a severity rating (see Bifulco et al. (2020) for a comprehensive overview of LEDS).

Herman (2015), has written widely around context and meaning arguing that key to understanding trauma is how and where it sits in social, political and historical discourses. Herman locates the first modern phase of investigating trauma in the work of Charcot, and others in the context of the “*republican, anticlerical political movements of late nineteenth century France*” (p12) with these wider social and political factors shaping the ways that trauma was understood. The second phase is in context of the rise of social and anti-war movements of the 1960s and in the emergence of second wave feminism with its emphasis on the shared experiences for women of sexual and violent trauma and the “*consciousness raising*” that was central to the movement. Today the dominant political discourses are those underpinned and informed by neoliberalism which, in the case of medicine, individualise suffering and disavow the social and the collective (Charmaz, 2019). These discourses

dovetail neatly with the increasing scope and power of technology, where the medicalisation of suffering provides the only route to legitimacy (Peacock et al., 2023). This inevitably informs how questions around the place of trauma and SSLEs are framed, what questions are asked and how.

We propose that trauma and SSLEs are more frequently associated with NEAD than many studies report, and that the links between such experiences and NEAD can be explicated and extended by understanding the “meaning” and context of the events rather than the contemporary narrow focus on prevalence or on trauma thresholds. Drawing on our data we show that none of our participants were event-free and in the discussion we explore the crucial role of context and meaning in understanding the nature and impact of trauma and SSLEs.

2.2.1. The study: methods

All aspects of our study were performed in compliance with relevant law and institutional guidelines. Ethical approval was obtained from the Yorkshire and the Humber Bradford-Leeds Research ethics committee (REC ref 19/YH/0169, granted 21.08.19) with research governance being provided by the Research Department of Sheffield Teaching Hospitals Foundation Trust.

Eligible participants had received a diagnosis of NEAD, based on seizure descriptions and relevant investigations, from a clinician (usually an experienced consultant neurologist) working within the neurology service for adults at Sheffield Teaching Hospitals and then placed on the psychotherapy waiting list. Diagnoses of NEAD were formulated on the basis of all available clinical data focusing on positive signs rather than the exclusion of other neurological disorders.

Potential participants were informed that the study concerned trauma, life events and NEAD, that they would initially be asked to complete a questionnaire and that some participants would then be invited to take part in interviews. Having provided written consent, participants completed the LiNES self-report questionnaire (Levita et al., 2019), with 8 high and 8 low scorers purposively sampled for FANI interview. Invitations, scoring, and categorising as high/low was done by JMD and CG; the rest of the team were blinded to the LiNES trauma scores of the participants until data analysis was complete (see supplementary data file for more detail). Of the 16 participants in the study, 15 were interviewed twice, and one person was interviewed once, the interviews lasted between one and two hours with a cut off end agreed with participants of two hours per interview. This use of the two methods also allowed for an exploration of what was elicited and understood as trauma when utilising a questionnaire measure and when using narrative.

Thirteen participants were interviewed in their own homes with three opting to be seen in the hospital which they attended for their diagnosis. Ten were women and six were men; slightly more men than the gender split found in larger studies (Goldstein et al., 2019; Sma-kowski et al., 2021) with an age range of 19–64 years old. (See Table 1). Most of the participants in the study were not working (mainly due to ill health) and in receipt of various sickness and disability benefits.

2.2.2. Rationale for the use of the FANI method

Our previous research (Peacock et al., 2022) showed that the FANI method was capable of eliciting descriptions of trauma and ALEs that participants had denied or disavowed, making it well suited to uncover unexpected and valuable insights in this trauma focused study. The FANI method (see Hollway & Jefferson, 2013) emerged in response to the limitations of survey research and the qualitative interview (as conventionally understood). Situated within a suite of “psycho-social” approaches, it aims to go beyond discourses and straightforward

Table 1

Nature and meaning of trauma and life events-as described by participants (anonymised).

Name-pseudonym	Trauma rating-FANI	Trauma rating-LiNES	Nature of trauma or life events
Chloe	High	High	19 years old. Very chaotic childhood. Indications of childhood abuse- physical and mental, including a memory of a potentially life threatening attempt by father to strangle her. Sense of being very outside in a reconstituted family. Very difficult relationship with her mother. Sexual assault and sexual threats/ stalking when in her later teens and unstable and unequal adult relationships. Traumatic breakup up post sexual assault. Loss of highly valued job due to seizures. These followed the sexual assault and loss of relationship. Concussions in childhood
Denise	Low	Low	64 years old. The most affluent participant-she had been a nurse, Her husband had made a lot of money from his building work. Two adult children-daughter who had had significant mental health problems for a number of years (now recovered) and an estranged son (his choice). Denise feels that the estrangement is a way to “punish” his father. Loving and happy childhood. Father had a severe and disabling stroke. Aphasic and wheelchair user till his death 10 years later. It was in the recovery phase from a stroke that the functional seizures started.
Pete	High	Low	42 years old and lived with his second wife in an adapted bungalow. Pete had a life changing RTA and brain injury at age 17 and, leukaemia diagnosis whilst still in hospital recovering from his injuries. Still significant problems relating to brain injury. Has a number of health problems-wears a leg brace, diabetes, sleep apnoea – “late effects” clinic for the leukaemia. Chronic pain. Depression and a degree of anxiety. Seizures started in the run up to his wedding-something he appeared to feel happy about and which was a form of salvation but which also caused numerous family problems. Childhood sometimes difficult-very challenging relationship with his mother.
Ann	Low	Low	57 years old. Ann had a dental clearance/multiple extraction of teeth and this was described by her as traumatic. Immediately preceded NEAD onset. Multiple pre and coexisting morbidities- fibromyalgia, Sjogren’s syndrome, migraine, Meniere’s disease, Raynaud’s, sinus tachycardia, pain and various surgical procedures on back and knees. Loving relationship with daughter and husband (a little fractious with

(continued on next page)

Table 1 (continued)

Name-pseudonym	Trauma rating-FANI	Trauma rating-LINES	Nature of trauma or life events
Dave	High	High	<p>husband who she feels doesn't understand her health problems). Family of origin not traumatic but quite tough and robust. Had to give up work due to disability or disability allowed her to give up work-not clear on direction of causality. 42 years old. Childhood sexual assault (female babysitter), mother very young when he was born and not able to cope. Trapped in and rescued from a traumatic house fire as a child (and blamed for setting the fire- he was clear this was not the case). Missed a great deal of school. Problem drug use and some self-harm as an adult. Pain and health problems-fibromyalgia. Dave found out that his birth father had Huntington's Disease when he was an adult and after the birth of his son. This preceded the NEAD.</p>
Eve	High	High	<p>50 years old. Childhood sexual abuse (more than one man). Serious neglect- did poorly at school. Intimate partner violence (severe) in adult life. Multiple losses (deaths)- sister, stepmother (much loved). Significant pain problems from beatings. Very obese with restricted mobility. Two cats- one of which is adored and relied on. Carer for her father- re-established the relationship as an adult. Adversely affected by the "bedroom tax"- living in poverty.</p>
Sue	High	Low	<p>52 years old. Has experienced a stroke. Some intimate partner violence including a blow to the head post stroke. OCD a major feature of her life as well as depression. Brother died from a stroke. Partner had a child with another person. Much loved dog being euthanised when she couldn't be there due to having to work as on a very low income. Sons who developed substance use and mental health problems (one found a person hanging- dead).</p>
Bethany	Low	Low	<p>27 years old. Bethany had significant life events which had powerful meanings for her- most notably the move from Europe and possibly anger and disappointment with her much-loved father. She cannot allow herself to acknowledge these feelings as it was his cardiovascular health and loss of his job that triggered the move.</p>
Carl	Low	Low	<p>52 years old. Only interviewed once due to return to work following recovery from surgery. Very quiet and flat in his presentation but witty and humorous at points. He has had X2 knee replacements (the second just a few weeks before the interview) and experienced</p>

Table 1 (continued)

Name-pseudonym	Trauma rating-FANI	Trauma rating-LINES	Nature of trauma or life events
Alan	Low	Low	<p>associated financial and logistical strains to do with work and access to benefits which were very demanding. Stroke and TIA and head injury in a fall. Very keen to return to work. 62 years old. Loving childhood and marriage. One adult son. Difficult to make sense of aspects of his self and functioning in the interview. Worked in retail and car sales but now unable to drive due to seizures. Appeared to have both epilepsy and NEAD. He had been informed by neurology that he had a recent and relatively significant brain injury which was a mystery to him and his wife- no history of head injury. Had an amnesic episode and other "odd" episodes as described by his wife.</p>
Kay	Low	Low	<p>43 years old. Very loving family of origin but a sense that this was quite anxious and over-protective. Mother had a heart condition and died when Kay was in her 20s. Kay is in a loving marriage, but her husband struggles to make sense of the seizures and finds them embarrassing. They started during lockdown. Long history of depression- hard for Kay to make sense of. Kay and her husband had a lot of fertility interventions but were unable to conceive which is a source of sadness.</p>
Sally	High	High	<p>63 years old. Persistent CSA by brother in the context of a severely neglectful and troubled childhood. Sister in care but Sally and brother seem to have been left together. Mother didn't believe her when she reported CSA. Brother now in prison for multiple CSA of children. Sally felt a sense of shame and guilt that she hadn't got people to listen to her account of what happened to her and thus failed to save others from his subsequent harm. Multiple health problems and is a wheelchair user. Long history of depression and intermittent alcohol problems. Significant pain problems and awaiting surgery. Very severe intimate partner violence, exploitative relationships-repeated throughout life.</p>
Tom	Low	High	<p>19 years old. Tom has a very loving relationship with his mother- who was present (with his consent) at the beginning of interview 1. He described a feeling of not being sufficiently attended to and safe as a child. He has some experiences of bullying due to his autism and has a stressful and challenging relationship with his father who will not "hear" Tom's experience of his autism (he doesn't live with him but visits regularly to see his half-brothers with whom he has a good relationship with as he does with his brother). Good relationship with his girlfriend and a close group of</p>

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Table 1 (continued)

Name-pseudonym	Trauma rating-FANI	Trauma rating-LINES	Nature of trauma or life events
Bill	High	High	<p>friends of long duration. Feels very excluded from services and was only able to access neurology due to a mental health crisis and his existing features of vulnerability.</p> <p>44 years old. Bill described developmental issues leading to bullying from very early childhood. He was unable to read until he was 7 or 8. Eventually went to a residential special school. Paternal violence in childhood and adolescence, repeated adult trauma and exploitation (x2 cuckooing). Bullying is a repeated and at times quite horrific feature of Bill's life. He is called a paedophile by neighbours, regularly exploited, falsely accused of a sexual assault, was raped by a stranger on his way home from work one morning. Bill has multiple physical health problems- asthma, knee problems and other and a long history of depression and self-harm (cutting), head injury.</p> <p>40 years old. Sarah came from a reasonably comfortable middle-class home. Father had some physical health problems and an explosive and sometimes terrifying temper. She described an incident of her father shaking her young brother and her mother screaming to stop as he would kill him. She described adolescent sexual assaults from the brother of her best friend repeated over time. When she disclosed this, the revelation was not handled well by her mother in particular.</p> <p>Married and moved to Australia- which was extremely stressful and precipitated her NEAD. Very difficult circumstances- lack of money, nowhere to live – when she returned.</p> <p>Talented textile artist- this includes the creation of art works about the death of a very close friend when they were both still in their 20s. Feels unheard.</p>
Sarah	High	High	<p>62 years old. Jill described unhappy but reasonably affluent parents who did not want kids. Her older sister was bearable to them, but Jill grew up very clearly knowing she was not wanted. Father volatile and physically abusive Including “punishment” with belt and at least one episode of beating to the head. Parents very cold and distant- especially mother.</p> <p>Jill very independent and left home very young but unable to survive financially and had to return. Worked for the police and married a police officer. Over time there were increasing levels of intimate partner violence. Husband's children from his first marriage started to live with them and his son began to sexually abuse her younger daughter. She</p>
Jill	High	High	

Table 1 (continued)

Name-pseudonym	Trauma rating-FANI	Trauma rating-LINES	Nature of trauma or life events
			<p>could not get husband to seek help or do anything about the abuse and so left with her kids.</p> <p>When her daughters were adults, Jill moved to the UK and worked in care settings and was bullied out of her most recent job and is now retired.</p> <p>Fibromyalgia/rheumatoid arthritis-pain problems. Feels unheard by medicine.</p>

accounts to “beneath the surface” of data to consider unconscious¹¹ as well as conscious processes shaping the interview process. The method uses multiple interviews with small numbers of participants, is open and exploratory using few questions structured to elicit narratives. Narratives can illustrate what the event(s) meant to the narrative giver as well as providing the context-they are not simply individual stories. As Greenhalgh has proposed, “Stories ... are told from a particular person's (or cultural group's) point of view and provide unique and nuanced insights into that person's (or group's) lifeworld and how they interpret it” (2016, P8).

Narratives, as elicited using FANI, are structured by the meaning frame of the participant, co-created in the context of the interview and grounded in real life events for more detail see the online supplementary file).

2.2.3. Data analysis using FANI principles

Central to the FANI method is the Data Analysis Group (DAG) which for this study was composed of two consultant neurologists (RAG and MR), an academic GP with an extended role (GPwER) in epilepsy (JMD) a neurological psychotherapist (CG) a medical sociologist (PB) and a research fellow (MP). The DAG met on 6 occasions throughout this study.

The data from each participant was initially analysed by MP (blinded to the LiNES scores). This phase of the analysis included all of the data relating to each participant (transcripts and audio) as well as reflexive notes and any other information supplied by participants (emails, written materials etc) enabling the production of a “Thoughts and Themes” document for each participant. The FANI method focuses first of all on the individuals' stories, holding these narratives intact rather than initially working across the data with this latter stage following the analysis of individual stories. In DAGs 1–5, the detailed individual narratives and the preliminary findings iteratively drawn from them were further explored for 12 participants to deepen, extend and triangulate the narratives. Because FANI does not readily lend itself to rating or scoring systems, we established a system to explore our findings in more detail and compare them with the LiNES numerical scores using a set of flexible principles based on described meanings and commonly understood event ratings to establish which participants might be considered high or low trauma. When the LiNES scores were revealed the determination of participants as high or low trauma were further reviewed and no ratings were changed.

In DAG meeting 6 the LINES scores were revealed to the whole DAG and an exploration of similarities and differences in LINES scores and

¹ It is important to emphasise that psycho-social approaches are not using the term “unconscious” in the Freudian sense of that which is deeply repressed from consciousness and only likely to be accessed by slips of the tongue or via psychoanalytic therapy. Here we mean that which is “beneath the surface”, similar to “preconscious” material as understood by Freud. This is more akin to lay understandings of what unconscious material is.

FANI data was discussed in depth. These processes were synthesised and summarised to produce the final, overall study findings.

Before presenting our findings, readers should be aware that we are quoting participants describing rapes, sexual assaults including childhood sexual abuse, and other potentially distressing material.

2.2.4. Findings

The findings presented below were synthesised in the course of the data analysis process described in the methods. Providing strong support for our argument that trauma and ALEs were found much more frequently than in studies using more conventional methods, the rich data which the method generated also raised challenges in presenting our findings in ways that adequately reflected this. Our division of participants into high and low trauma groups provided a lens through which to examine the nature of trauma and we selected data examples which we felt best illustrate this key distinction.

We developed two key emergent themes during the data analysis process; firstly the salience of the nature and meaning of traumatic events, and secondly the importance of time, place and context in how participants framed their narratives.

Participants with “high” trauma (PwHT).

There were nine people who had experienced high levels of trauma with eight of these having experienced either physical assaults or what Goleva (2020) terms “serious sexual assault trauma” which includes sexual assaults in childhood or adult life and sexualised stalking (See Table 1). Amongst this group was a subset of people (Eve, Dave and Sally), who had experienced severe neglect in childhood alongside sexual abuse as well as other severe and significant events. All three lived in desperate poverty and described childhood social services involvement but not in ways that they felt helped them. These were the people who then went on to experience the most severe and repeated trauma and SSLEs throughout or later in life.

2.2.5. Participants with “low” trauma (PwLT)

The seven PwLT had not experienced the sexual assaults and the violence and neglect in childhood found in those with high trauma. There were descriptions of childhoods which were tough and challenging but not the severe neglect and abuse found in those we describe as high trauma individuals. This absence of severe childhood trauma was the most striking difference between the two groups. As adults the most frequent events that precipitated or perpetuated seizures for the PwLT were health related or connected to a significant life change or relationship challenges.

2.2.6. The nature and meaning of the traumatic events and SSLEs

2.2.6.1. *Sexual and violent trauma.* The experience of sexual and violent trauma was the main divider between the two groups, described by all the high trauma participants and absent in all the low trauma participants. Dave, neglected as a child by his mother, described sexual abuse from a female babysitter when he was nine years old;

“there’s still loads I haven’t told you, like being [sexually] abused by my babysitter she was like thirteen so ... but the things that she used to get me to do, has put me off sex for life, I don’t like sex [she used to get me to] finger her, erm, lick her out, she used to get me to wee in her mouth, put my fingers up her bum.”

Sue experienced sexualised stalking both as a teenager and as an adult (completely separate incidents and not involving the same person) as well as a period of intimate partner violence;

“I used to get these phone calls, ‘I’ve seen what you’re wearing today, you look beautiful, you’ve got a really nice bum’ and that and then I used to get things posted through the letterbox, like Durex’s [condoms] and things like that.”

Sally was exposed as an adult and as a child to very severe and damaging harm, having suffered sexual abuse, violence and neglect in childhood and sexual assaults and intimate partner violence (IPV) in adult life leading to problematic alcohol use and other difficulties. Here she is describing one of the many incidents of IPV;

He [Ex partner] literally battered me. For six months, I was in a collar, my face was unrecognisable. And then I lost a kidneyHe kicked me like a football. And my womb and my ovaries were all stuck together, it was a mass, they were so damaged”.

Bill who had developmental issues from childhood and a lifelong history of bullying and abuse, often of a sexualised nature, described a stranger rape - one of many violent and sexually abusive experiences that he suffered;

“I did a night shift and when it finished, when it became daylight, I would normally walk down this alley way. I said morning to this bloke, thinking be polite, the next minute I got pulled down onto the floor, this bloke was quite big and stocky, he had all piercings in his ear and the next minute he ripped my trousers open, and I felt violated.

MP: Were you raped?

“Yeah. I got home, I didn’t tell my wife, I just got straight in the bath, I was scrubbing myself and I made myself virtually bleed because I felt dirty and I bottled it up, I didn’t even tell my dad or my sisters.”

2.2.6.2. *Health, illness and pain.* All the high trauma participants except Sarah (highest level of education, in full time, highly skilled work) described multiple health problems both physical and mental. Pain, often experienced as severe, chronic and debilitating, was a feature for all but two of the PwHT and by many PwLT. Pain presented further challenges to legitimacy as many felt as though their pain was seen as less credible due to their NEAD diagnoses, with prescribers encouraging them to wean themselves off their (usually opioid) medication. Here Dave is describing his fibromyalgia diagnosis from a rheumatologist;

“the thing is with fibromyalgia ... no one knows anything about it. He went ‘right you’ve got fibromyalgia’He just like told me and that was it ... and then he went ‘good luck with getting your pain medication’ he says cause they’re really thingy and he said ‘if I was you I’d try cannabis’ I thought ‘oh my god’.”

High rates of comorbidities and especially mental health comorbidities are well established in those with NEAD and were described by the PwLT as well as the PwHT. Health related issues were frequently salient as precipitants for the former and often included a sense of a fear of being unheard or abandoned. Here Ann (PwLT) is describing the total dental clearance that immediately preceded the onset of her seizures;

*“So, I says, how long will it take? He went, ten to fifteen minutes. I went, right, fine, ok, just get on with it. There were four dentists working on me at the same time. And, it took them an hour and three quarters to get them out. And, after they did it, they just walked away and left me. No, are you alright Ann? Do you need anything? **They just walked away and left me.**” (emphasis added as she had stressed this part in the interview.)*

Going on to say when describing another procedure, “All I can think of, whilst they’re doing it, is somebody please hold my hand. But no, there was nobody there to hold my hand ...”

In addition to the pain was the sense of being unheard and let down in the context of a relationship with health professionals where there was an expectation or hope of care and a distressing breach of this expectation when it did not occur.

2.2.7. *The relational and contextual salience of trauma and SSLE’s in NEAD.* Not all experiences of trauma, however severe, appear to be salient for the development of seizures. Our data showed, consistent

with other research (Griffiths et al., 1998; Nicholson et al., 2016), that salient traumas are relational - that is, those events that occur in relation to people with whom there is a relationship of intimacy (parents, carers, close friends or relatives, partners; those people whom the person trusts and where there is a hope and an expectation of compassion or safety) or agencies and individuals in agencies where there are similar investments. In relation to the latter, the most common is clinical medicine as an agency and individual doctors as a manifestation of that hope and of those investments. More “impersonal” traumas such as natural disasters or accidents may be damaging, possibly severely, to people but they are unlikely to initiate or maintain seizures. Pete, for example, described the onset of his seizures in recent years in the context of significant relational stressors concerning his family. As a teenager he was seriously injured in a road traffic accident whilst cycling and during the many months he spent in hospital being treated for his injuries, he developed leukaemia. Despite the severity of these early traumas they did not precipitate seizures arguably because, they are not relational traumas.

The wider social context is also important to understanding how participants appraised their experiences. Sue received threats and experienced sexualised violence and IPV by men but these occurred, we would argue, in a context where they were considered to be part of the anticipated experience of women - a form of epistemic injustice (Fricker, 2007). Scoring as low trauma on the LiNES scale with this self - appraisal, Sue comments that her partner, “*didn't beat me up where I'd got black eyes*”, as though clarifying that the blows to her head soon after her experience of a stroke were somehow mitigated as they were not something as severe as other forms of IPV. She goes on to describe an assault when she was thirteen,

“I went out one day and got attacked. He ripped my top, he ripped my bra, scratched me a few times. So I went into my dad, police came and it made me really ill ... it caused loads and loads of problems ... and then my dad ended up in a fight. He used to go to a club ... [and] my dad had heard one of the guys saying “well I can understand why they picked Sue out of the rest of them because like she's a nice looking lass and she's got a better personality” So then my dad flipped ...”.

his reflects a culture where violence against women and girls is explained in relation to the properties of the victim - “*nice looking lass*” and is thus excusable and naturalised - a form of what Bourdieu terms “symbolic violence” (Schubert, 2014, pp. 179–194). It seems unlikely that her assailant was aware of nor interested in her personality when he attacked her.

2.2.7.1. Time and place. The salience of place and temporality in understanding trauma became clear as we analysed the participant narratives and noted how much these factors ran through what they told us. Participants shared experiences which arose and were shaped by where they lived and what these areas had endured. The places where much of the data for this study were collected were ex-mining areas which experienced catastrophic social, political and economic damage in the decades since the miners' strike of 1984 and subsequent pit closures and job losses. A report commissioned by the Coalfields Regeneration Trust (Beatty et al., 2019) found high rates of child poverty, ill health, unemployment, limiting long term illnesses (LLTIs) alongside increased crime and drug related deaths, in comparison with other equally deprived areas; a powerful illustration of the destruction of social cohesion and loss of hope as long term consequences of deindustrialisation and their impacts on health (Price et al., 2024). These shifts serve to increase the likelihood of trauma exposure and its consequences as participants explain;

“My [teenage] son found a man hanging dead down the canal. He phoned the police and he'd been there four days, the police said, said to him can you cut him down and he says ‘no I can't cut him down’ [my son] wouldn't have counselling. Since then he's started sleeping with

knives and things and that underneath his bed and underneath his pillow ... and he's paranoid.” (Sue).

“My best friend was my cousin, he died. Then, three of my best friends who I knew growing up have all died. I've had one hung himself, one died of a car crash, one died of pancreatitis, one died of heroin overdose, one died in a motorbike accident” (Dave)

These traumatic exposures to multiple losses through death and to the damaging behaviour of others (drug use, violence) consequential on the loss of work, cohesion and fractured social bonds in these areas, are place and context related, outside individual agency and not attributable to individual pathology.

3. Discussion

As Charmaz (2019) argues, “*The narratives of individuals are important not only for their insights concerning their immediate situations but also for what these narratives say about the structures affecting their lives.*” The FANI method elicited narratives without preconceptions of what might constitute trauma and ASLEs. This resulted in rich data concerning the nature, meaning and salience of events, allowing for better understanding of the relationships between such events and NEAD, increasing understanding of social factors and trauma exposure and indicating what might differentiate or be common to both high and low trauma participants. What our results clearly show is that the trauma/no trauma dichotomy, as understood in many studies is an over-simplification of a complex set of questions concerning the place of life events and trauma in NEAD, and further that this complexity is arguably underestimated in clinical interviews. Focusing on trauma thresholds, definitions of which frequently vary across studies, misses the salience of meaning and of context, depleting rather than deepening understanding. Attending to events in context and what they mean to the person can help to make sense of what properties salient to NEAD such events might have in common and to see how the timing and nature of events feature as predisposing, precipitating and perpetuating factors.

For our participants trauma and adverse life events were prominent features of lives. Not all participants had experienced trauma, however defined, but all had experienced adverse life events that they connected in their narratives with their experiences of NEAD. And equally as not all trauma is specific to NEAD and it is ‘relational trauma’ that appears to be salient, understanding the nature of trauma rather than whether a trauma threshold has been met which is, we would argue, key to understanding.

Trauma and ALEs can act as predisposing, precipitating or perpetuating features for NEAD. The severe sexual and violent experiences in childhood found in the PwHT are probably not best understood as precipitants as they were distant in time from onset but rather may act as a form of kindling or sensitisation creating vulnerabilities with which later events can connect. Or they may initiate damaging social and relational processes that lead to greater trauma exposure and harm throughout the life course. The combination of childhood sexual abuse (CSA) with neglect seems to be a particularly damaging combination (Hingray et al., 2022; Salmon et al., 2003). Sexual assault as an adult is known to be a precipitant and for those who were sexually assaulted in childhood, adult assaults may serve as a recapitulation or re-experiencing of the initial trauma (Beghi et al., 2020; Govleva et al., 2020). Sexual assaults are an extreme form of a relational trauma but for most people in this study, trauma and SSLEs were relational in the contexts of childhood and adult experiences such as breaches of trust, hope and expectations. These relational qualities are key for both PwHT and PwLT and are central to understanding what might connect life events and trauma. A focus on trauma thresholds may result in failing to see that it is salience and meaning and who or what the trauma is in relation to, which determine the extent and nature of the consequences.

Findings from other studies indicate aspects of these relational qualities; Nicholson et al. (2016), extended the LEDS scale in their work

with functional disorder, creating a category of “*escape events*”, which were much more commonly encountered than in their control groups. Such events “*estimate[d] the extent to which the impact of a stressor might be ameliorated by being ill with neurological symptoms*” (p 2619) with the authors theorising that these events could result in forms of “*secondary gain*” in facilitating escape from stressors. Griffith, and PollesGriffith (1998) described “*unspeakable dilemmas*”, which could be avoided or sidestepped by the (unconscious) generation of seizure symptoms. These shared properties of salient events, their relational qualities and the importance of meaning also feature in our findings.

Similarities and differences in the nature of trauma exposure may also indicate that there are subtypes or subgroups within those diagnosed with NEAD. Hingray et al. (2022¹) identified three subgroups differentiated by trauma history and proposed that this perspective might, “*facilitate the development of more specific therapeutic programs for each ... profile*” (p 1500). Because of our small sample we cannot map our findings precisely onto their model but there are some very interesting comparisons with their work and the patterns of trauma that we found. The authors also show is how much of the trauma burden in their study were sexual assaults in both childhood and adult life, and that CSA has the potential to be a necessary and sufficient condition for the development of NEAD without any further trauma - patterns which we also saw.

As well as the nature and meaning of events, our findings show that who is exposed to which experiences and the resources available to mitigate or protect are situated in and shaped by the wider social and political context. The social gradient in trauma exposure is underreported and underdeveloped in most contemporary theorising about NEAD despite extensive evidence from health inequalities research of the sharp differences in exposure between affluent and less affluent areas. Numerous studies have shown the “*clear impact*” of poverty on the incidence of Adverse Childhood Experiences (ACES) including abuse and neglect (Marmot et al., 2020) and the US provides some very sharp examples with Kravitz-Wirtz et al. (2022) finding that young people in the US from Black or Latinx backgrounds (proxy marker for disadvantaged neighbourhoods) were three to seven times more likely to be exposed to gun violence than those in more affluent neighbourhoods. The social and political contexts in which people live, not simply their actions, results in exposure to structural violence and harm and play a significant part in the experience of trauma as both witness and victim (Galtung, 1999; Price et al., 2024). Without an inclusion of context, a depleted view of trauma as embodied within the individual prevails, limiting understanding.

The study participants, whilst not ‘representative’, reflect many features of people presenting to hospital neurology services and receiving diagnoses of NEAD. There may be limits to the generalisability of this group to all of those experiencing NEAD, composed as it was, of those with a secure diagnosis in a specialist centre and on the psychotherapy waiting list. However, there is much that is arguably likely to be relevant to the wider population.

4. Conclusion

The findings of this study add to the growing body of work that focuses on meaning and salience in understanding the place of life events and trauma in NEAD. Both are more frequently present in NEAD than many studies appear to indicate. It is how the data is collected and what is understood to be trauma which primarily determines what is reported in the literature. Future research could focus on utilising and developing the sorts of data collection and theoretical approaches which we have shown extend understandings and indicate ways in which such finding could impact on clinical practice. Clinical interviews and questionnaires which focus on trauma thresholds do not appear to be adequate in accurately establishing the presence or absence of trauma nor its nature and salience. Sexual assault traumas are so frequently encountered that assessment and treatment orientations could consider adopting trauma

and violence informed approaches (Ford-Gilboe et al., 2018). Whilst trauma is not experienced by everyone with NEAD and there are differences between those with high and low levels of trauma, our data show that for all, life events and their context are relevant.

People/participants live and suffer in a world of relationships and social connections with expectations and investments; how these are understood shapes what is found and what is considered to fall within the purview of NEAD. Excluding or marginalising relational, social, political and contextual factors distorts and depletes understanding of trauma and life events. Including and developing ways to identify and integrate these factors has the potential to deepen and extend understanding and influence the mode of treatment.

CRediT authorship contribution statement

Marian Peacock: Writing – review & editing, Writing – original draft, Visualization, Validation, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Paul Bissell:** Writing – review & editing, Visualization, Validation, Methodology, Investigation, Funding acquisition, Formal analysis. **Markus Reuber:** Writing – review & editing, Visualization, Validation, Resources, Methodology, Investigation, Formal analysis. **Cordelia Gray:** Writing – review & editing, Visualization, Validation, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation. **Richard Grünewald:** Writing – review & editing, Visualization, Validation, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis. **Jon M. Dickson:** Writing – review & editing, Visualization, Validation, Supervision, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization.

Data statement

Due to the very detailed nature of the data from the narrative interviews we cannot place these in a data repository and preserve anonymity. Please contact the authors to discuss data access arrangements.

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Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

Markus Reuber reports a relationship with Elsevier that includes: employment. Markus Reuber reports a relationship with UCB and UCB Pharma that includes: funding grants and speaking and lecture fees. Markus Reuber reports a relationship with Jazz Pharmaceuticals Inc that includes: I have declared this in a previous page but just to be clear Markus Reuber has a relationship with Elsevier as he is paid as Editor in Chief of Seizure. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

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