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Beyond the medical encounter: can the Free Association Narrative Interview method extend psychosocial understandings of Non-epileptic Attack Disorder? An exploratory study.

Abstract

This exploratory interdisciplinary study was devised to explore how using the Free Association Narrative Interview (FANI) method might extend understanding of Non-Epileptic Attack Disorder (NEAD) within a psychosocial framework. NEAD is the medical definition of what can be described as embodied events that resemble epilepsy, but which are not associated with the abnormal electrical discharges in the brain found in epilepsy. They are the most frequent “functional” disorder or medically unexplained symptom (MUS) seen by neurologists.

Whilst NEAD is associated with trauma, distress and negative life events, a significant minority of patients report no trauma history. The FANI method, we argue, produced narratives which shed light on events which patients had not acknowledged as traumatic, but which might be considered as such, and we explore what aspects of the method may facilitate this process. Previous work highlighted that a diagnosis of NEAD is often experienced as deeply troubling and contentious to both give and to receive, we thus reflect on the need for patients to feel a sense of legitimacy and how the challenges of living with a NEAD diagnosis were negotiated.

Drawing on the work of Benjamin (2004) on “thirdness”, we suggest that the FANI method can allow the research interview to become a space which facilitates novel ways of engaging around NEAD. We conclude that FANI may be a powerful tool for studying NEAD, and that further studies should be undertaken using this approach since it may have broader utility in understanding the landscape of functional neurological disorders.

Key words

Embodiment, psychogenic seizures, Non-epileptic Attack Disorder, , functional neurological disorders, psycho-social approaches

Introduction

In this paper, we reflect on the use of the Free Association Narrative Interview method (FANI), drawing on the findings from a small exploratory study, and its potential for extending contemporary understanding of Non-Epileptic Attack Disorder (NEAD). NEAD is a functional neurological disorder (FND) and is the most frequent "functional" disorder or medically unexplained symptom (MUS) seen by neurologists with an estimated 20% of patients first presenting to seizure clinics receiving a diagnosis of NEAD (Stone et al., 2016). The process of acquiring a diagnosis of NEAD may be troubling or difficult, and patients often experience a range of inappropriate treatments and interventions which can result in iatrogenic illness and with considerable distress or frustration accompanying the diagnostic process for some.

The FANI method has been used in a wide range of studies, notably in health and in criminology, (Gadd 2007; Garfield 2010; Hollway & Jefferson 2013; Vicario et al 2021, and others) and has been shown to be particularly useful in researching areas which are troubling, sensitive, likely to engender shame and where participants may experience a need to *"account"* for themselves. The method aims to facilitate the exploration of what has been described as "defended" positions, accessing thoughts, narratives, emotions and interpretations. Underpinning these processes is the idea of the “defended” subject understood as *“a psycho-social subject, drawing on psychoanalytic concepts that* *emphasise unconscious conflict, defences against anxiety and the centrality of unconscious intersubjective dynamics in the research, as in other relationships*" (Hollway 2001, p 9), and its counterpart, the defended researcher. Given this orientation towards understanding defensive anxieties, we hypothesised that FANI might be a promising methodological tool to bring to bear on a contentious area such as NEAD. This paper reports on and summarises the findings from a small exploratory study, using FANI interviews to better understand people's experience of acquiring a diagnosis and of trauma and life events in the aetiology of NEAD.

NEAD (also known as dissociative, conversion, functional or Psychogenic Non-Epileptic Seizures (PNES) or, more pejoratively, "pseudoseizures") are embodied events that can resemble epileptic seizures, but which are not associated with the abnormal electrical discharges in the brain found in epilepsy. Instead, NEAD is considered to be an involuntary emotional response to internal or external triggers. These sorts of seizures do not arise from structural abnormalities of the nervous system or neurological disorders and are understood to have a psychological and/or social basis, often connected to histories of trauma or negative life events.

Characterised by episodic impairment of consciousness and loss of motor control, NEAD is frequently mistaken for epileptic seizures or fainting, although closer analysis of subjective and objective manifestations reveals many differences between these disorders (Brown and Reuber 2016a; Dickson et al 2017). NEAD can result in significant and chronic disability and risk of exposure to inappropriate investigations or treatments and thus major iatrogenic harm.

There remain important gaps in understanding this complex condition as Rawlings and Reuber (2016 pp 283] comment*, "Research has only given limited attention to the subjective symptomatology of NEAD ...neglecting patients' symptoms and experiences".* Many studies have used self-report questionnaires which cannot capture the heterogeneous and subjective nature of the seizures and their context and there has been no work to our knowledge that has used a narrative approach to researching NEAD, although there has been interest in the narratives that patients with NEAD and those with MUS construct to make sense of their experiences (Nettleton et al., 2005; Rawlings and Reuber 2016; Reuber et al 2018). There is also a dearth of published research examining the wider socio-cultural dimensions that shape the contemporary construction and experience of NEAD. A WHO report (Greenhalgh 2016) commented that, "*Individual stories* ***are nested within wider meta-narratives****"* (P8, emphasis in the original). By "meta-narratives" Greenhalgh means the wider social and cultural contexts within which biographies unfold, illustrating this with an example from the wider report explaining that, "refugees' narratives capture *"a shared past experience of separation, loss, physical hardship, discrimination, poverty, and persecution, all of which may be crucially important influences upon the nature and course of the illness")* (P 8). It is these meta-narratives which we hoped the FANI method might also facilitate access.

This distinctive aspect of FANI; the premise that whilst individual biography is unique, we can best understand it when it is located in its social, historical and political context means that the method readily lends itself to thinking psycho-socially (with the emphasis here on the social) about the individual life story. Thus, we anticipated that the FANI approach might produce new complementary and clinically important insights and understandings.

In this paper we use examples from our data including the place of childhood sexual abuse and traumatic events and readers should be aware of this.

The FANI method

The FANI method (Hollway and Jefferson 2013) initially emerged in response to the limitations of both survey research and the qualitative interview (as conventionally understood). What is characteristic of the FANI approach and what led us to consider that its use might bring new understandings of NEAD was its focus on the holding together of the psychic and the social- uncommon in most qualitative approaches. The method has been described at length elsewhere (Hollway, 2001; Hollway and Jefferson, 2013) and we would advise readers to explore these sources. Since its inception by Hollway and Jefferson (2001) the method or adaptations of the method have been used to explore a wide range of issues, but notably those arguably characterised by experiences of shame or contestation or where defences might be likely to be invoked. Vicario et al, (2021), for example, looked at the way women talked about alcohol consumption in the post-partum period; Capri (2018) explored the experiences of people with intellectual disorders and Stenning (2018) has used psychogeographical approaches and a modified FANI method to detail the lived experience of "austerity" in the UK focusing on place and, *"the psychosocial aspects of these experiences, attachments, values, practices, spaces, senses and times that need to be understood by holding together the psychic and the social"* (P 200).

As well as exploring the utility of the FANI method we also aimed to add to knowledge about NEAD and its aetiology. Specifically, we wondered if the FANI method could make a key contribution to answering an important question about those who initially report “no trauma” when the diagnosis of NEAD has been made: was trauma not present and did different mechanisms (unrelated to trauma) lead to NEAD or has trauma simply not been recognised, reported or defended against by participants?

The study

All participants in this study were recruited in via the epilepsy services in Sheffield, United Kingdom. They had been diagnosed with NEAD in hospital by epileptologists on the basis of seizure descriptions as well as investigations including Magnetic Resonance Imaging of the brain, electroencephalography (EEG), video and video-EEG recordings of typical seizures. Ethical approval was obtained from the University of Sheffield Research Ethics Committee. The study aimed to recruit a total of six participants. One individual only engaged on the phone so five individuals took part in face-to-face interviews. Participants were interviewed on three occasions (a total of 15 interviews) with interviews varying from one to two hours in duration. Three of the participants were seen at their homes and two in a hospital outpatient department with participants choosing which setting they preferred.

All interviews were audio recorded, transcribed in full and analysed using the FANI approach. All the members of our interdisciplinary study team participated in the data analysis group, which is a key feature of the data analysis process. The team was composed of two specialist neurologists [MR and RG], a GP neurology specialist [JD], specialist neurological psychotherapist, and a medical sociologist [PB] alongside the research fellow [MP] who conducted the primary analysis and undertook the interviews. In the analysis both the audio and written transcripts were used to facilitate contrast and comparison between the data sources. Reflexive notes were kept throughout the study and these, alongside a range of materials (emails, texts, written notes) which were provided spontaneously by participants, were included in the analysis.

From this initial stage detailed pen portraits of the participants were developed along with preliminary themes. These were taken to the data analysis group, which operated using FANI principles, refining and triangulating the themes across the data, exploring and reflecting upon meaning and connecting themes with theory and with clinical experience. Pseudonyms are used below in detailing the narratives of the participants.

Understanding NEAD

A comprehensive exploration of the history, aetiology, incidence and prevalence of NEAD is outside the scope of this paper, however, in order to make sense of the study findings, a brief exploration of the disorder is necessary and, in particular, what is currently understood about the place of trauma.

Studies consistently show that around three quarters of those with a diagnosis of NEAD are women and that NEAD appears to be linked with histories of neglect, trauma and stressors in childhood including childhood sexual abuse (CSA) which is reported by 20-30% of women and 5% of men in different patient cohorts (McKenzie et al., 2010; Myers et al 2017). As well as childhood trauma, trauma and increased rates of adverse life events, are found throughout the life course often serving to precipitate the onset of NEAD in adulthood (Reuber et al 2007; Fiszman et al 2004), but nonetheless there appears to be a significant minority who do not report trauma (Ludwig et al., 2018). This may be because trauma is not present, or because it is present but is not understood as trauma by the person, or is unconsciously disavowed or defended against, or present but not readily accessible to be reflected on in a clinical or research setting.

There may be good reasons to "deny" trauma; trauma is, almost by definition, likely to be difficult to talk about and, in cases of childhood sexual abuse (CSA) or severe neglect, even more challenging and problematic. It is only in recent years that the nature and scale of abuse has become more widely acknowledged and many people with such experiences may fear not being believed or not seeming to be legitimate and there are often anxieties about being judged that can result in feelings of shame and guilt or fear of the consequences of disclosure.

There are also higher rates of psychiatric co-morbidities, somatisation, dissociation, avoidant coping tendencies and difficulties in describing and accessing feelings and emotions consistently found in those with NEAD (Rawlings and Reuber 2016). And for many NEAD represents a considerable illness burden to the person themselves and often to those around them (Reuber and Brown 2017) with many people being unable to work or experiencing themselves as disabled by the condition and its consequences (Dickinson et al 2012). A recent study (Goldstein et al 2020) found that three quarters of their participants were in receipt of state benefits and there are some indications that there is a socioeconomic gradient in NEAD with over half of the participants in the same study living in the two most deprived areas of the UK compared to 11% in the least deprived.

Thus, trauma or serious life events are one part of a complex interactional picture but better understanding the place of trauma in NEAD, what sorts of traumas might be most salient to NEAD and why there may be people with NEAD who have not experienced trauma can help to shed light on the condition as a whole and the people and the places in which it occurs.

The place of trauma, life events and stressors

To understand trauma requires a definition of trauma; Scaer, in *The Body Bears the Burden* (2014, p 5) defines trauma as *“a perceived life threat in the face of helplessness”.* The “perceived” is helpful here as it brings in the meaning and significance of the traumatic event(s) to the person. Scaer goes on to say that, in relation to dissociative conditions, trauma is usually more harmful if it involves other people who are involved with or salient to the person in comparison to traumas such as natural disasters or serious accidents. Salient people may be loved ones but may also include figures where trust is invested such as doctors.

NEAD shares common ground with earlier understandings of bodily manifestations of suffering or unspoken emotional or psychological experiences such as hysteria. Space does not permit a detailed exploration of hysteria and its connections with what we understand today as psychogenic seizures or FNDs but, arguably, both are frequently connected to the experience of trauma and, in particular, sexual and abusive trauma. Freud, in developing his seduction theory argued that *"At the bottom of every case of hysteria there are one or more occurrences of premature sexual experience”,* (1896/1924.

p. 203). Despite later disavowals of the reality of sexual abuse in childhood and a shift to proposing that these disclosures were fantasies, he argued at the time that *"I believe that this is an important finding, the discovery of a caput Nili [Source of the Nile] in neuropathology."* However, since Freud the place of trauma and sexual trauma in NEAD/FND has waxed and waned in its centrality and acceptability as an explanator. More recently there has been an increase in studies that explore the presence or absence of trauma in NEAD and the nature of trauma likely to be salient to its aetiology and maintenance (Ludwig et al 2018 ; Goleva 2020; Myers 2018). The latter two papers also show the much higher rates of sexual abuse and assault amongst women with functional seizures, with Goleva finding rates of PTSD and sexual assault 16 times more frequently than a general hospital patient control group and Myers finding 42% of women with NEAD reported sexual assault, with 88% of these events happening before the age of 18, compared to 18.3% in the general population.

Early life and subsequent life stresses (stressors are likely to share some common ground with trauma) are also found amongst those with epilepsy both in precipitating seizures (Novakova 2013) and in increased rates of diagnosis in those with serious life stressors such as the loss of a child (Van Campen 2013). But these are not at the rates found in NEAD and some studies have also found increased rates of brain abnormalities such as cerebrovascular disease (Govleva 2020) in those with NEAD. This illustrates well the complex interaction of trauma and stress resulting in physiological changes in the brain and how brain abnormalities may increase rates of stressors. As Goleva (2020, p 10) puts it, *"Taken together, these findings provide evidence for the hypothesis that functional seizures, while influenced by multiple complex factors exhibiting interindividual* *differences, may be considered a physical manifestation of the neurological damage caused by trauma."* This perspective also flags up the need to avoid narrow and dualistic dichotomies of mind and body in understanding the relationships between trauma and illness.

Findings

There are two areas of our findings from this study which we focus on in this paper. These are, the presence trauma and specifically what we refer to as denied or unacknowledged trauma in the biographical accounts of some of the participants and secondly, how participants experienced their journey through services and in particular, the process of receiving a diagnosis.

Below we provide brief biographies of three of the participants to provide a context for what we illustrate in the data we present.

Joyce, aged fifty-six, was married with a very supportive partner. From the age of five, she was sexually abused by her father with this abuse continuing into her adult life and marriage- only ending and disclosed after his death. From her early twenties she described experiencing multiple physical problems which impacted on her capacity to work, and which resulted in a range of invasive medical interventions and numerous experiences of surgery (gall bladder removal, gastrointestinal surgeries, two brain surgeries), none of which resolved her symptoms. She had a diagnosis of fibromyalgia and experienced chronic pain. As an adult she had several traumatic bereavements and negative life events. The onset of her seizures, both she and her husband felt, connected with her mother's death and a battle with the hospital to acknowledge responsibility for the associated failures of care.

Maxine aged forty-three did not identify any traumatic events connected to her seizure onset. During the interviews, it emerged that her husband had died a rapid and very distressing death five years previously, after many years of problematic alcohol use. Maxine had had to give up a "good job" as an accountant to look after him and their children. She had gone back to work in a large clothing store for the first time since her husband had died- a job which she needed but intensely disliked. The seizures had started three months into the new job with first onset occurring at work.

Chrissie aged sixty-four was in a second marriage with very supportive partner. She described experiencing, "fainting fits" for many years before these became diagnosed as NEAD. Chrissie also described some joint pain and restricted mobility and the effect of the NEAD diagnosis was to have closed her world down as she could no longer drive. Like Maxine she did not identify trauma in adult life and had been shocked to be asked about childhood sexual abuse in the course of her symptoms being investigated. Despite the disavowal of any trauma, it transpired in the interviews, that her daughter from her first marriage had left home at sixteen having got involved with 'a bad lot' and Chrissie had had virtually no subsequent contact with her. As an adult, the daughter had been severely beaten, knifed, and left for dead in a back alley in what seemed to be a gang revenge attack. Chrissie had visited her in hospital, but no reconciliation had occurred or seemed wanted.

Findings

The presence or absence of trauma

Establishing the presence or absence of trauma is important in understanding the underpinnings of NEAD. In using the FANI method in this study, probably the most striking finding was participants who did not refer to (significant) trauma in either adult life or in childhood but then went on to detail events, when narrating their biographical stories, that are arguably better understood as traumatic.

Trauma explored

Amongst all the participants, the FANI method served to open up exploration very readily, including those with an acknowledged trauma history. In interview two, Joyce talked about the sexual abuse by her father having obliquely flagged this at the end of the first. There was a feeling of checking out that the researcher and the research space were sufficiently containing to make such a conversation possible.

"*I always think of myself:* ***you're gonna click on here****, I'm a survivor not a victim"* (emphasis added, Joyce)

Having established that the researcher would be likely to *"click on"* (that is, to understand that the victim or survivor divide referred to sexual abuse in childhood) it was then possible in the second and third interviews to talk about this and the shadow cast over her and her family's lives,

"my dad … he sexually abused me, he sexually abused my niece ... and I'm not sure if he sexually abused [another niece] *who died, because as far as I know she turned to drugs and she died in a coma. We … think that's what happened to her. But ... she came to see me ... and said, 'Auntie, before I get married, I need to tell you something.' And she told me that her granddad had sexually abused her".* (Joyce)

The extent and nature of the trauma was also apparent, *I felt guilty because I let it carry on while I were married...I said to him, 'One of these days, Dad, I will stick a knife through you.' He said, 'God put you on this earth for me.' … I says, 'Every time you say sorry, you don't know what the word sorry is.' I said, 'It's not love, it's lust with you.'* (Joyce)

Trauma denied; what the method can bring

Denial or lack of awareness of trauma was most apparent with Maxine and Chrissie. Turning first to Maxine whose husband had died of an alcohol-related condition in his early forties. Maxine had given up work to care for him and their children a year before his death and subsequently suffered depression (a fact that emerged only when she mentioned taking antidepressants). Her return to work, for the first time since he died, in a low paid job that she hated created powerfully ambivalent feelings and a sense of her being trapped and it was at work that her seizures began. During the second interview the possibility that she could have been grieving and may have feelings of pain and rage at his loss and its context emerged,

> *"I don't know. I suppose it could be, I mean… yeah. I don't know, I've never thought of it like that… never even put two and two together like that. You know what I mean? I've just presumed that… I've just been putting things and getting on with everything now. You know what I mean? And, yeah, I have got all… I were getting over it, you know what I mean. I don't suppose I'll ever really get over everything....But I've never even thought that it could be anything like that.* "(Maxine).

Chrissie explicitly disavowed any trauma, either as an adult or in childhood. It was during the first interview, as part of the researcher checking her understanding of Chrissie's family structure, the issue of whether she had had children with her first husband came up. At that point she explained that she had a daughter from that relationship (she has a very close and warm relationship with her daughter from her second marriage) but she did not see that daughter or speak of her. After some tentative exploration of whether it was acceptable to explore this further, she described telling her daughter to leave at the age of 16 after she fell in with *"a bad lot".* She then described her daughter becoming involved in the periphery of gang culture and then agreeing to testify in a trial going on to say,

"she gave evidence against one who were shooting somebody. She had been warned to keep out of it: anyway, she didn't, she gave evidence. So that night somebody found her in the backs in [City] *and they'd machete'd her. Anyway, whoever found her wrapped her up in bin-bags which saved her life"* (Chrissie).

Chrissie visited her daughter in hospital after the assault but when her daughter was dismissive towards her, left, and has seen virtually nothing of her since. This was retold in a calm and contained manner with neither distress nor detachment apparent and sat very oddly with Chrissie's warmth and kindness that was otherwise manifest. There was a strong sense that Chrissie did not perceive her experiences of and with her daughter as in any way traumatic or could not readily access painful or traumatic feelings in this domain.

Whilst the small number of participants in this study means that it is not possible to generalise about the proportions of those with NEAD who have trauma histories, "trauma denied" or no identifiable trauma history, what the study does indicate is that the FANI method can be an effective tool in eliciting narratives of what might be considered trauma even when the person does not identify trauma in their life and thus can serve to extend understanding of the place of trauma and its likely underreporting in NEAD.

We now move onto outlining how participants experienced the journey from experiencing symptoms to diagnosis.

The diagnostic journey

Whilst better understanding the place of trauma had been an aim of the study, there was a second key finding, present to some extent in the narratives of all participants, of the vagaries and struggles of acquiring and living with a diagnosis of NEAD. Space does not permit a detailed exploration of this finding nor room to provide richer biographical materials- we aim to cover this finding more comprehensively elsewhere and here outline what we encountered.

Diagnosing NEAD often involves a process of exclusion with physical factors being considered first and NEAD being the default diagnosis when other possibilities appear implausible. Most patients are initially told they may have epilepsy or another organic condition. When investigations are completed and no significant pathology is identified, when treatment fails to work or more information about the seizures becomes available from patient or witness reports or video recordings, the subject of NEAD and their "psychological" underpinning may be raised. This process can leave patients confused and sometimes unwilling to accept psychological treatment even when this is offered (Carton et al., 2003). It also locates the origins of NEAD within the patients' psychological make-up, which can be experienced as troubling and hard to make sense of.

Thus, understanding experiences of the journey through services is important for two primary reasons. Firstly, it allows for the identification of points where confusion or uncertainty are encountered, facilitating the possibility of change to, for example, improve communication or change aspects of the diagnostic process. Secondly, it sheds light on the dialogical processes between clinical medicine and patient perspectives and how these might shape the understanding and management of the condition.

Obtaining a diagnosis

The psychological aspects of a NEAD diagnosis can be experienced as troubling (or may be resisted) and even patients who are open to psychological explanations may struggle to see how their symptoms have a psychological basis (Thompson et al., 2009; Monzoni et al 2011a). They may be told that the condition is stress-related but may not perceive themselves as being "stressed", and there may be concerns that the "real" nature of the symptoms is not being acknowledged, a fear that they are being seen as hypochondriacal or malingering, or anxiety that a "real" medical condition has been missed. As Natalie, a teacher with no known trauma history says,

"I had an EEG and that come back all right and [the consultant] *were like 'It must be psychological' and that's… that's all I know…So in the back of my head I'm thinking: Is it still psychological or is it more……either an illness, like an infection?"*

And this can extend further into a fear that no matter what the person said, their view will not be listened to,

"So ... when I'd read a bit about it and I saw, 'You're gonna be in denial,' this, that and t'other or a bit like… ooh, like… don't say, 'I don't believe you,' (Natalie)

For Maxine there was a strong sense of confusion about the diagnosis, but also a sense that this confusion served to keep her away from an explanation that she was very uncomfortable with, *"So nothing's actually been diagnosed, that's why they've said it must be……non-epileptic attack. Is it migraine, is it epilepsy, is it non-epileptic attacks? I'm just like… well, what the hell is it? You know what I mean? I just want something to say… I'm still thinking what's a matter with me? You know what I mean? Am I going crackers? Am I this? Am I that?"* (Maxine)

Chrissie had understood what eventually became NEAD, to be what she thought of as "blackouts" or "fainting fits". Having had some heart problems, the blackouts came to light and were investigated, though this did not seem to be something that she had particularly sought. The emergence of the diagnosis was protracted, and she was very vague and nebulous in her descriptions with "seizure" or "fit" being terms that she was not comfortable with using. Describing her admission for assessment,

"He put all things…on my head. ...on the Tuesday afternoon, I think, I had one [a seizure]*....* *So* [the consultant] *said, 'Well, we've got what we want and it is a non-epileptic thing.'"* (Chrissie)

The diagnosis for Chrissie seemed to be something that she was uncomfortable with to the point of being unwilling to name it. This difficulty with naming was also identified by Plug et al., (2009), proposing that, *"many patients with NEAD exhibit some degree of interactional resistance to use the term seizure"* (pp 106). In the case of Chrissie, this reluctance could be explained, in part, by her diagnosis being abruptly shifted from fainting fits (a non-stigmatising diagnosis) to an unsought one of NEAD and a reconstituting these events as "seizures".

For others there was frustration or concerns that those around the person with the condition do not understand what it is (with an unspoken sub-text suspecting that people were not interested enough to find out or they disbelieved that the condition was legitimate). This was apparent in Sally's (who had a long history of somatising conditions) experience of routine clinic appointments:

"They do not understand NEAD – nobody I have met from… even doctors, even at my surgery they've never seen it. The younger ones I've asked, I've had Registrars and I always say, 'Have you ever seen a NEADs sufferer? Have you ever witnessed an attack?' and they say, 'Erm… ooh, no.'" (Sally).

These accounts provide some important insights into participants' views of the communication difficulties, differing appraisals of what is most important or salient in understanding the condition, and the fears, that constitute the gap between the subjective illness experience and the conventional biomedical paradigm (Rawlings et al 2017).

Discussion

Understanding the place of trauma and trauma denied or unacknowledged was a key aim of this study and our work has shown that FANI can readily open up a space where this can be explored and has resulted in some indicative novel findings, bearing in mind the limitations of such a small study. We would want to be clear and cautious here, the absence of trauma cannot be assumed to be trauma denied or unacknowledged. There are indications from our and other studies that rates of trauma and severe stressors are very high in those with NEAD and our study indicates that trauma can be disavowed or unacknowledged. But there remain indications that not all of those with NEAD have experienced trauma and this is also significant.

A second finding concerning the experience of acquiring and living with a diagnosis of NEAD is consistent with the extant literature and shows something of the troubling, painful and often baffling encounters with contemporary biomedicine. Dickinson et al (2011) and Fairclough et al (2014) have shown many of those with NEAD diagnoses experience themselves as not being heard or being dismissed because of the uncertain nature of their condition and their symptoms. In addition, given the contested and often unwanted nature of the diagnosis, it may mean that there is some resistance to "hearing" communications with concerns that no matter what the clinician says or what tests show, there is an underlying organic or physical problem that is, as yet, undetected and which would be more readily acceptable than a diagnosis of NEAD. The FANI method may be less freighted with anxiety and expectation than the medical encounter and thus able to open a window on the world of NEAD. With this in mind, we propose that the FANI interview facilitates the co-creation of a *"third space"* where new ways of considering NEAD, without the immediate evoking of defensive resistance or entrenched positions that often occur in "medical" settings. This “third space” has both literal and metaphorical properties. In a literal sense, the research interview is a third space because it is not rooted in clinical medicine, psychiatry or therapy and thus serves to evoke fewer pre-determined expectations of what might be ‘done’ in this space akin to that described by Harris (2019). What we primarily mean as a third space is taken from Jessica Benjamin and her work on *“thirdness”* in the psychoanalytic encounter and how this has been applied by psycho-social theorists to the potential of the research interview. For Benjamin, thirdness is *"a* *quality or experience of intersubjective relatedness that has as its correlate a certain kind of internal mental space"* (Benjamin, 2004 pp7). This thirdness goes beyond the dynamics of many encounters where *"there appear to be only two choices: either submission or resistance to the other's demand…*[where] *the two are irreconcilable, as in "Either I'm crazy or you are"* (p 10). By contrast, thirdness is contingent upon mutual recognition and a moving beyond the feeling of one person being the "doer" and the other the "done to" (the title of Benjamin's paper addressing thirdness). Hoggett (2010) in his work with community workers using FANI interviews, proposed that, *"the research interview can be a recognition-producing exercise in which the respondent has the experience of "...being understood""* (pp183). In addition, in the NEAD study reported here, the FANI method arguably not only facilitated the experience of being understood, it also allowed space for exploration of uncertainties and ambivalence about diagnosis or feelings of not being understood or heard.

This may contrast sharply with many medical encounters concerning NEAD or MUS which are often experienced as contested spaces Authors own [2011b]. This contestation is such that the metaphors found in the literature looking at the clinical consultation are rich in imagery of battle and polarised opposition. Werner and Malterud (2003) use the image of the *"law court"* with the patient as defendant to be scrutinised for credibility, with Salmon (2007) drawing on images of *"medieval sieges"* to be won by the side whose resistance lasts longest. The FANI method as used in this study, with its emphasis on attending to narratives shaped by and delivered on the terrain of the participant was, we propose, *recognition-producing* in ways that allow for less defended forms of dialogue. That is, the nature of both the space and the dynamic, reflexive character of the research conversation, allowed for the consideration and exploration of how NEAD might be understood without the immediate evocation of pre-existing patterns of resistance.

It is arguable that all qualitative research has the potential to create a space in which the topic at hand can be explored, and indeed, this is one of the commonly claimed strengths of the qualitative paradigm (Silverman 2011). However, we are suggesting here that the recognition-producing features of FANI, which in part lie in its drawing upon of some of the principles of the therapeutic encounter, facilitates a thirdness, as understood by Benjamin. This allows for an exploration of experience that is in a different register to both conventional qualitative research *and* the medical / clinical interview. In the case of NEAD (and potentially other health issues where there is a sharp divide between patient and medical narratives) this third space has a particular utility in stepping to the side of some of the defences that necessarily come into play in the face of the medical gaze.

Because of the biographical nature of the interviews, the meta-narratives that Greenhalgh (2016) referred to also enter the frame of the FANI interview. In the case of NEAD, this was primarily seen around the intense anxieties which were expressed around legitimacy, and we would argue that these cannot be meaningfully understood without being situated alongside the discursive shifts of recent years about the legitimacy of illness and disability in the UK. Symptoms are delivered by patients onto the terrain of biomedicine but if symptoms are not established to have an identifiable organic basis there is then often a struggle for understanding and legitimacy. In the case of NEAD, patients often seek an organic explanation for their symptoms (or one which fits within what they consider to be legitimate) and resist "psychological" alternatives - but regardless of explanation, symptoms remain and have to be accounted for. What is clear is that the clinical encounter can be a very troubling place, arguably iatrogenic (Salmon 2007) where patients will accede to doctors' explanations of test results and other matters considered to be within their domain of expertise, but where psychological explanations are frequently resisted as being insufficient or an inappropriate response to the patient's suffering and, importantly, a place where open discussion can be very difficult to achieve (Monzoni et al 2011c). The space for interactional conflict – and dissatisfaction and disappointment - is considerable.

Fox (1980) has proposed that the more that clinical medicine advances, the harder it becomes to bear and to understand clinical uncertainty. Others have gone further and argued that this continuing advance *"aggravates the very insecurities that they are designed to quell"* (Crawford 2004, p 506, cited in Nettleton 2006, p 1169). These uncertainties and the anxiety created through this process are woven through the experience of diagnosis and living with NEAD. There is a considerable body of sociological theorising that argues that such anxieties are a prominent feature of living in late modernity (Bauman 2013). More recently, we would contend, the need for medical legitimacy has moved to centre stage with a growth in the imperative for those who are chronically ill or disabled to ensure that they are legitimately occupying these positions (Authors own 2014.). These shifts may serve to deepen and maintain the mind-body dualism so characteristic of the biomedical model, which is played out in the clinical medical encounter when striving to address such conditions as NEAD. Nettleton writing in 2006 proposed that *"people who live with illness that lacks any biomedical explanation form an extreme instance of the experiences that people face more generally in* *contemporary society"* (p 1175). More than a decade later, we would propose that this is even more troubling than when Nettleton was writing.

Conclusion

Locating NEAD in the broader psycho-social and methodological landscapes explored above indicated to us the potential of FANI to improve understanding, particularly across disciplinary boundaries. The method opens up new ways of understanding the narratives of patients, through the recognition-producing qualities of the FANI interview facilitating the emergence, in some participants, of stories which can be considered to be traumatic, but were unacknowledged. Establishing that trauma can be made visible when narrative methods are used may have value in both clinical and research practice. Using narrative approaches in the clinical setting may make possible both the identification of traumatic or distressing events that may be relevant to NEAD, and the use of narrative may be a tool for talking about the events.

Whilst this was a small study, the findings concerning trauma and the diagnostic journey are promising indicators of FANI's potential as a research tool within this clinical area. The ways in which we have used the work of Benjamin and “thirdness” to indicate the sorts of work that can occur in an encounter concerning difficult and defended positions, has the potential to be extended to the places and spaces where the clinical or treatment encounter occurs. However, there are likely to be considerable challenges in transposing a research tool into a clinical setting. Nevertheless, using a narrative-based approach in both research and in clinical interviewing, may elicit more detailed information about the extent and nature of trauma, and open-up the possibility of exploring why trauma may be unacknowledged. FANI as a research tool can illuminate aspects of meaning and experience for those with NEAD and thus extend understandings of aetiology. Larger studies could provide information to help to shape innovative ways of establishing the sort of therapeutic liaison with patients that allows for less contested clinical encounters and help to make sense of the complex ways in which the condition is understood and managed in practice.

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