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Northern Network *for*  
Medical Humanities

## Non-Epileptic Attack Disorder: Metaphysics, Epistemology and Ontology

The proceedings of a workshop held at the  
Humanities Research Institute, The University of  
Sheffield, on Friday 18<sup>th</sup> October 2019.

## Introduction

There is no satisfactory medical explanation for non-epileptic attack disorder (NEAD). People who are affected lose consciousness, collapse and convulse. The condition is often mistaken for epilepsy, but it is not associated with abnormal electrical activity in the brain, EEGs and brain scans are normal. The condition was recently the subject of a feature film called [Dis-sociated](#) which is available on YouTube. In this workshop, funded by the Northern Network for Medical Humanities Research (NNMHR), we invited a diverse interdisciplinary group of doctors, philosophers, sociologists, and psychotherapists to ask if radically different ways of thinking about NEAD may help us to make sense of this troubling illness. In particular, we aimed to take a philosophical perspective, and to think about the metaphysical, epistemological and ontological frameworks that shape thinking about the condition, and how they might be different. Our aim was that the workshop would lead to a proposal for a philosophically informed research project which could benefit patients and practitioners. In the morning we heard from our invited speakers and, in the afternoon we held a discussion amongst the speakers and our delegates. This document is our record of the workshop.

I'd like to thank all of our speakers and delegates, the day was characterised by a compassionate and thoughtful mood. The presentations were beautifully crafted, complimentary and synergistic. This is the first event I am aware of which has involved such a diverse group who therefore have a unique perspective on NEAD. I think the reader will agree that this interdisciplinary and philosophically informed approach has shown possible new directions for future research.

Finally, many thanks to the NNMHR who provided funding and made the workshop possible. We are very grateful for their support.



**Jon M Dickson**  
14 May 2020  
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**Jon M Dickson** is a GP, a senior Clinical Lecturer at the University of Sheffield and an expert in seizure disorders. He works in the epilepsy clinic at Sheffield Teaching Hospitals NHS Foundation Trust and has published over 20 articles in peer-reviewed scientific journals. He appears in the feature film Dis-sociated.

**Richard A Grünewald** has been a Consultant Neurologist at Sheffield Teaching Hospitals NHS Foundation Trust since 1995. He has particular interests in movement disorders, epilepsy and medically-unexplained neurological symptoms, and has run a clinic for patients with medically unexplained symptoms for 18 years. He contributed to NICE guidelines on chronic fatigue syndrome and has published over 150 peer-reviewed papers over the years.

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**Cordelia Gray** is a Specialist Psychotherapist working for the Sheffield Neurology Psychotherapy Service for five years. She works with patients with functional neurological disorders (including non-epileptic seizures). She has been a psychotherapist for 16 years, specialising in complex trauma and has a special interest in research with this patient group.

**Marian Peacock** is a Senior Lecturer in Public Health at Edge Hill University whose research interests are in how inequality gets inside the body and the place of neoliberalism. She is the qualitative interviewer on the current NEAD study "My seizures, My life" and she appears in the film Dis-sociated.

**Paul Bissell** works at the intersection between public health and medical sociology. He is interested in how we can use advanced qualitative methods, such as the free association narrative interview method, to research sensitive or difficult experiences.

**Annamaria Carusi** is Reader in Medical Humanities at the University of Sheffield. She has a broad humanities background, and specialises in the philosophy and sociology of medical knowledge, and biomedical research.

**Patrick Bracken** is a Consultant Psychiatrist and he was Clinical Director of the West Cork Mental Health Service, in Ireland, until 2016. He now works on a freelance basis and is currently working as a consultant with the WHO. He also has a background in philosophy and is known for promoting the importance of 'critical thinking' in mental health work.

## Epilepsy and the Biomedical Paradigm – Richard A Grünewald

Our understanding of the nature of seizures has been dominated for years by the concept of epilepsy, which was recognized as a brain disease by Hippocrates. Proof that it was a disease of the brain came from the work of physiologist Fritsch (1838–1927) and psychiatrist Hitzig (1838–1907); in their paper entitled “On the Electric Excitability of the Cerebrum”<sup>1</sup> they presented experiments in which they provoked seizures by electric stimulation in the brain cortex of dogs.

John Hughlings Jackson (1835–1911), set the scientific basis of epileptology. Jackson studied epilepsy on pathological and anatomical basis. His ‘Study of Convulsions’ was the culmination of his research stressing the existence of localised lesions in the cerebral cortex involved in epileptic convulsions. In 1873, Jackson gave the following definition for epilepsy: “Epilepsy is the name for occasional, sudden, excessive, rapid and local discharges of grey matter”.

Assurance that that the disorder is associated with abnormal electric activity in the brain came from Gibbs and Lennox, who published an important monograph in 1941 “Atlas of Electroencephalography” which established the relationship between EEG changes and seizures. Earlier, Penfield and Jasper had distinguished ‘centrencephalic epilepsy’ from focal epilepsy on EEG grounds, an important step in sub-categorising of the epilepsies. Current explanations of the pathophysiology of epilepsy have evolved somewhat and now centre upon hypersynchronous electrical communication between neurones and neuronal networks in the brain.

With the idea that abnormal brain activity was the substrate for epilepsy came the idea that brain surgery might be curative. Surgery for epilepsy was tried occasionally from about 1880, but the idea of operating on an epileptogenic focus was introduced by Gibbs and Lennox in 1938<sup>2</sup>. In 1934, Penfield and Jasper introduced the Montreal procedure for the surgical treatment of epilepsy. Through the administration of local anaesthetic, the surgeon removed part of the skull to expose brain tissue and, by the use of probes, the conscious patient described to the surgeon his/her feelings so that the surgeon can identify the exact location of seizure activity. Then the surgeon proceeded in the removal of brain tissue in this location reducing the side effects of surgery. Through his operations, at the same time Penfield was able to identify various brain centres and to create maps of the sensory and motor parts of the brain. This led to the paradigm that the brain had ‘centres’ for various mental and physical capacities, which can be seen as a development of the 19<sup>th</sup> century ideas of phrenology.

Further bolstering of the concept of epilepsy as a biophysical disorder came from the recognition that it could be treated with drugs. Antiepileptic drug treatment was tried from the second half of the 19<sup>th</sup> century (potassium bromide, various herbal remedies). In 1912 phenobarbital was introduced, in 1938 phenytoin followed by many others. There are now 20 or so antiepileptic drugs, each of moderate efficacy in some epilepsies as defined by reduction in frequency and severity of seizures. For those who are poorly responsive to drug treatment, there are now various surgical options that are fuelled by advances in neuroimaging (MRI, PET and MEG)<sup>3</sup> which can be correlated with EEG abnormalities to define more or less precisely the site of onset of seizures and therefore the surgical target.

In 1969, members of ILAE and a preliminary classification of epilepsies was presented to a commission on terminology of epilepsy. The General Assembly of the ILAE accepted the first publication of clinical and electroencephalographic classification of epileptic seizures<sup>4</sup>.

Despite the sophistication of electroencephalographic and neuroimaging techniques, there are many patients who have epilepsy but no underlying structural abnormality detectable in the brain. In such cases the condition is considered likely to be genetically determined, perhaps through an abnormality of neurochemical or biophysical function. To complicate the matter further, there are organic seizures which are not detectable by surface electroencephalography, so it is possible to have epilepsy with entirely normal neuroimaging and EEG. The idea that all seizures were physically determined had a powerful hold on neurological thought for many decades, and it was only within the last 10 years that it has been universally recognised that dissociative attacks are psychogenic rather than electrogenic. In some cases, however, clinical differentiation between epilepsy and dissociative seizures remains

uncertain, as the diagnosis depends heavily upon descriptions of seizures from eyewitnesses and video recordings.

What is NEAD: Explanations that work for me – Richard A Grünewald

Psychogenic non epileptic seizures, also known as pseudoseizures and non-epileptic attacks are now recognized as common in the epilepsy clinic, representing about 30% of our clinical workload. A precise definition and delineation from other forms of seizure sometimes difficult, but a useful working definition is that they are attacks that resemble or may be mistaken for epileptic seizures but which are not associated with measurable change in brain physiology and instead have a known or presumed psychological cause.

Non-epileptic attacks are heterogeneous, but by far the commonest type is the dissociative event. This has a marked relationship with trauma, and there are descriptions of such events in the literature concerning patients with shell shock returning to the UK after the first world war<sup>5</sup>. Other types of NEAD include emotional outbursts (more common amongst those with learning disability), malingering or manipulative behavior or as part of factitious disorder.

Diagnosis of NEAD depends on clinical acumen and rests largely on descriptions provided by the patient and witnesses. Descriptions of dissociative events are characteristically bland, with the patient unable to provide much information about the phenomenology of the attacks, the duration or their frequency. Instead, patients may concentrate on their impact. Witnesses describe attacks that may vary one from another in appearance, duration and severity. Very prolonged attacks may occur, there may be partial awareness and responsiveness and resistance to eye opening during the attack, and emotionality (particularly crying) afterwards.

The relationship of such events with psychological trauma is somewhat contentious<sup>6</sup>. With appropriate cues, about 80% of patients in our clinical service will acknowledge a history of trauma. I use a simple definition of trauma (box 1) and emphasize the difference between this and stress. In this context dissociation can be seen as a reflex protective mechanism to limit the impact of memories of trauma and associated emotions, i.e. occurring in the place of flashbacks.

Box 1

<p><b>Trauma definition for clinic:</b></p> <ol style="list-style-type: none"><li><b>1. Events are outside personal control</b></li><li><b>2. Unacceptable or intolerable</b></li></ol> <p><b>Such events result in the acquisition of a memory that is very enduring (possibly because the memory trace is made more persistent by the emotional component), but which is distressing and disruptive if it is consciously recalled</b></p>
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This explanation, despite its limitations, is widely accepted by patients. Important features of the explanation that contribute to its acceptance by patients is a straightforward, matter of fact approach to the explanation, a clear emphasis on the symptoms being reactive and outside personal control, and that the attacks are a normal psychological defense mechanism which enables people to cope with higher levels of trauma than they could otherwise tolerate. If patients acknowledge that the explanation has personal relevance they are then offered psychotherapy and an assurance of an optimistic prognosis.

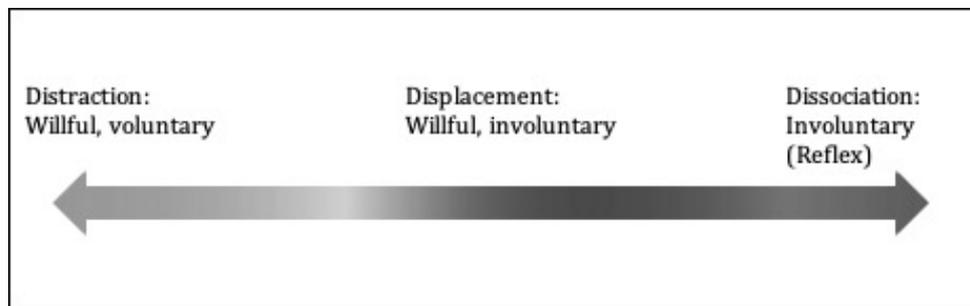
Although some patients readily acknowledge trauma, and some disclose traumatic events to me in clinic (occasionally for the first time) a significant minority deny any history of psychological trauma. This is a particularly interesting subgroup, and is heterogeneous in nature. Some patients resist acknowledging the significance of events that occurred many years ago and which they have put behind them, and some are not aware of the emotional impact of events in their lives and some are unwilling to share painful biographical details with doctor or others in the consulting room. In those who do attend for psychotherapy, some may take many sessions to develop a relationship with the therapist that is secure enough to disclose trauma.

Part of the clinical discussion I offer is an elucidation of the process of dissociation. This is often treated superficially in clinical consultations, and it is my impression that patients value a clear and simple explanation. The model I use places dissociation at the extreme of a spectrum of normal human responses to uncomfortable thoughts, feelings and experiences (box 2). Everyone is familiar with the idea of distracting himself or herself from something unpleasant, for example by listening to movement when they go for a run in the park. Less often considered, but almost equally familiar is the concept of displacement, which most individuals can try for themselves by casting their mind back to an extremely embarrassing incident in their lives, for example when they are driving a car. In such circumstance they may find that they have involuntarily doing something to drive the recollection out of consciousness, for example coughing, humming or turning up the radio. Others witnessing this behavior may question what it is about. Similar automatic displacement activities occur when people swear in response to pain or 'tut' when they find something irritating.

Dissociation can be seen as the most extreme end of this spectrum, occurring in individuals who have experienced events that are very disturbing to recall, often because of intense feelings of shame, disgust or anger. In these circumstances there is an automatic switching of attention away from the memory to internal experiences and perceptions. However, echoes of the traumatic events that triggered the dissociation may be apparent in the physical movements that accompany the dissociation (i.e. pelvic thrusting, side-to-side head movements or striking out) and the emotional context may outlast the dissociation, giving rise to emotional upset afterwards.

A sensitive, simple and clear explanation of the mechanism of dissociation and of NEAD is likely to be an important landmark in the initiation of recovery from trauma. It is important the people are empowered to see these attacks as a consequence of events in their lives and that the symptoms afflict them for a reason. Without such an explanation patients are likely to feel that their lives are blighted not only by their personal experiences of trauma but also by the development of mysterious and inexplicable symptoms which cannot be addressed personally or with the help of clinicians.

Box 2



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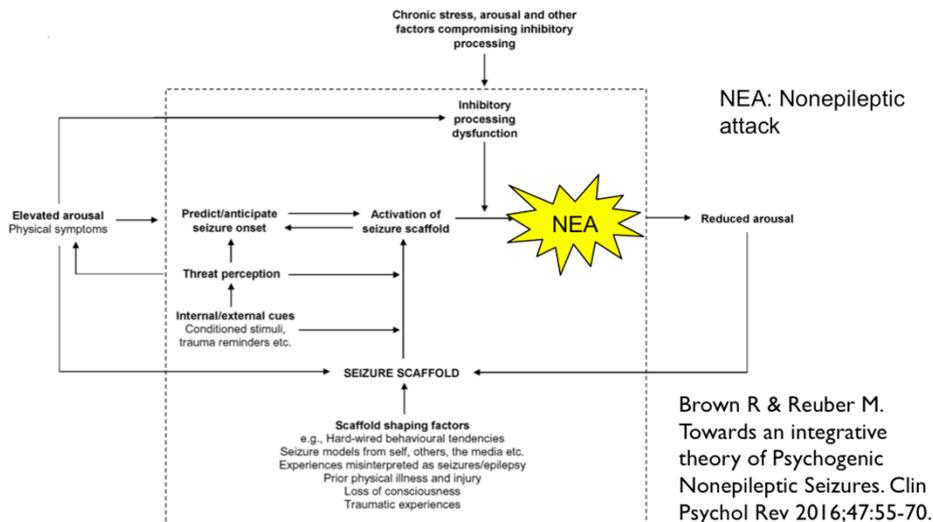
Non-epileptic attack disorder: An integrative cognitive model - Markus Reuber

In the recent international nosologies of mental disorders, most patients who are given the label of Nonepileptic Attack Disorder (NEAD) fulfill the diagnostic criteria of a dissociative or conversion disorder<sup>1,2</sup>. In 2016 we completed a systematic review of the evidence supporting these and other models of NEAD (also known as Psychogenic Nonepileptic Seizures). The review appraised the literature on life adversity, dissociation, anxiety, suggestibility, attentional dysfunction, family/relationship problems, insecure attachment, defense mechanisms, somatization/conversion, coping, emotion regulation, alexithymia, emotional processing, symptom modelling, learning and expectancy in patients with NEAD<sup>3,4</sup>. Although the poor quality of many of the reviewed studies limited our ability to draw firm conclusions, it was clear that none of the traditional models (variably interpreting NEAD as the activation of dissociated material, a physical manifestation of emotional distress, a hard-wired reflex response, or learned behaviour), could fully account for the phenomenology of NEAD or for the results of experimental studies in this patient group. The lack of a comprehensive and specific model of NEAD is not only problematic from a scientific point of view but also because it makes it harder for clinicians to explain the disorder to patients.

The findings of our review led us to propose an Integrative Cognitive Model (ICM) that brings together existing theories within a single explanatory framework. The ICM gives rise to a number of novel hypotheses and questions which should prompt further research<sup>4</sup>. Perhaps more importantly, it also provides an acceptable and scientifically grounded model of NEAD which can be communicated to patients and used to explain why the treatment of choice (i.e. psychotherapy) may work.

Inspired by an older theory of “medically unexplained symptoms” (MUS)<sup>5</sup>, the ICM interprets the observable and subjective elements of NEAD as resulting from the automatic activation of a learnt mental representation (i.e. the "idea" of seizures). Within the ICM this representation is called the "seizure scaffold". This scaffold is typically activated in the context of an inhibitory dysfunction resulting from chronic stress, arousal and other factors that compromise higher level cognitive processing.

Figure 1: The Integrative Cognitive Model (ICM) of NEAD



The seizure scaffold consists of a sequence of perceptions and motor activities initially formed by experiences such as in-born reflexes (eg. freeze, startle), physical symptoms (eg. of pre-syncope / dissociation / hyperventilation), but also personal knowledge and modelling. The perceptions may be triggered by sensory inputs but are generated by pre-existing expectations and do not match patients' actual internal or external environment. The predominance of expectations over sensory inputs characterizing NEAD experiences is very much in keeping with that seen in other functional disorders<sup>6</sup>. This sequence of perceptions and actions is relatively stable but not completely fixed. As such, it has much in common with the key constituents of a conditioned reflex.

Like other conditioned reflexes, the seizure scaffold can be triggered by different internal or external stimuli. This may occur in response to elevated autonomic arousal, although the triggering process can become divorced from abnormal autonomic and emotional activity and may be triggered by thoughts or perceptions which are, objectively, quite neutral and non-threatening. The process of triggering the seizure scaffold often disrupts the individual's (full) awareness of distressing material and their surroundings. The seizure scaffold is more likely to be triggered in the presence of weakened inhibition, which could be due to chronic stress but also have "physical" causes such as illness or the effects of medication. Patients typically experience the launch of the seizure scaffold as non-volitional although they may be able to inhibit it by willed action. This is in keeping with the observation that there may be times when patients "wilfully submit" to the dissociation associated with their PNES by a withdrawal of active inhibition subjectively perceived as volitional <sup>7</sup>.

The reflex-like nature of seizures in NEAD which is described in this model is consistent with the observation of a limited number of NEA-types and the relatively stable experiential and behavioural semiology of seizures in individual patients <sup>8</sup>. However, the ICM can accommodate the clinical and psychological heterogeneity evident from so many of the studies discussed above, while indicating how factors such as previous traumatic experiences, current life adversity and physical health problems contribute to NEAD. Importantly none of these factors is essential for the development or maintenance of the disorder, even though they may be of central importance in specific cases. Patients find this model acceptable because they realize that reflexes are not carried out "deliberately" although many can be willfully suppressed. Importantly, this model does not depend on patients being aware of a traumatic predisposing or precipitating factors although the model readily accommodates trauma and neglect if these factors are aetiologically relevant.

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## Psychotherapy for NEAD, My Perspective by Cordelia Gray

### *Context of the Specialist Neurology Psychotherapy Service in Sheffield (STH NHS Foundation Trust)*

The Specialist Neurology Psychotherapy Service has a Psychotherapy manager and six psychotherapists who are trained in multiple different schools of psychotherapy. Consultant Neurologists refer patients with FNSD (including NEAD) to the service with exclusion criteria including: suicidality, already receiving therapy elsewhere, dependence on alcohol or opiate drugs or serious psychiatric problems requiring input from a psychiatrist. Patients are assessed and then seen for up to 20 sessions, the number of sessions is agreed between patient and therapist. The team has an agreed ethos of working in an integrative manner. Working relationally with patients, developing the therapeutic alliance, grounding, stabilisation and psycho-education are agreed integral parts of how this team works with FNSD. Therapeutic approaches are combined and tailored to individual patient's needs and preferences based on a wealth of experience working with FNSD patients since 2011.\*

### *What is Psychotherapy?*

Psychotherapy helps a person understand patterns, behaviours, unconscious processes and how these may affect their everyday life. In therapy a person looks at the impact of significant events on their lives (which may or may not include explicit trauma) and how key relationships have shaped their beliefs about the world and their place in it. It offers the opportunity to reflect on tightly held beliefs and patterns and to make changes, make meaning of experiences and hopefully find acceptance and compassion for themselves and their current circumstances. It also looks at their social, political and cultural context and how this affects their life experiences.

Patterns that are established and repeated over time can lead to fixed responses to situations. Psychotherapists help a patient to be curious about what purpose a symptom might be serving. More often we would work with the patient to help them understand the relational context of their life experience. How their experience of growing up has affected them, what emotions were acceptable, what feelings weren't allowed, what role did they play in the family? Etc. These patterns develop out of awareness and the symptoms that develop are an unconscious response. For example, a woman who had witnessed domestic violence between her parents which was still on-going, with a culture of denial in relation to this. In our work together we explored the devastating impact of her parent's dysfunctional relationship and the family denial of any problems. This had left her questioning her own sanity, feeling constantly anxious and doubting her natural responses to others. She was extremely anxious in her own relationship and felt she had to work really hard all the time with her children and husband. She had NEAD and together we looked at what unconsciously her seizures might be offering her. She started to recognise that the seizures offered a chance to rest and be looked after: they were the only time that she stopped. Reflecting on this enabled her to start to build more time for herself into her life and to ask for help in more direct ways. This led to a reduction in her seizures. This was not in her conscious control, however, in starting to understand how confusing and frightening her early experiences were, she was able to find ways to stabilise and ground herself when she felt anxious in other relationships. Understanding the terrible impact of her history and in particular the denial that anything had happened, helped her to develop new patterns of relating to others, setting down clearer boundaries about what she could and couldn't do and to start to ask for help more directly.

My training is in Integrative Arts Psychotherapy. This involves the integration of a number of different theories of human beings. My particular integration includes Psycho-dynamic, Gestalt, Jungian, Transactional Analysis and body psychotherapy perspectives. It is informed by third wave Cognitive Behavioural Therapy models in particular ACT and Compassion Focussed Therapy and by mindfulness based practices. At the core of my thinking, from Buddhist philosophy, is the assumption that being human brings suffering. The longer a person lives in the world the more likely they will be to experience suffering; they will experience loss, pain, disillusionment, despair and ultimately their own death. Most humans spend their lives trying to avoid or deny these feeling states. This denial can take many forms including addiction, over-work, over-caring, avoidance and distraction (for example compulsive shopping). Feeling states that are allowed, tend to dissipate over time, those that are denied tend to fester and cause harm. For example, a patient reported the death of his dog and that he had allowed himself to cry and mourn the loss. Prior to therapy another dog had died and he hadn't been able to feel any emotion around this but had worked even harder than usual. He reflected that this led to a

build-up of emotions and angry outbursts with no sense of relief or space for his grief. Therapy helped him to reflect on his pattern of bottling up his emotions and the negative impact that had on him emotionally, relationally and physically in particular in exacerbating his dissociative symptoms.

My training includes using the Arts to help patients to reflect on their patterns. This could be through the exploration of dreams, drawings, poems, postcards, objects and sensations in their body. The aim is to help the person to connect to an 'inner knowing' and is based on the idea that the psyche knows what it needs. This idea is familiar in Jungian philosophy and in Art Therapy theory. 'The soul is a very perfect judge of her own motions, if your mind does not dictate to her....The soul's deepest will is to preserve its own integrity, against the mind and the whole mass of disintegrating forces.' D.H.Lawrence (1923). Too often people have a belief that if I just try really hard I can change things, if I just do x or y then everything will be alright. You may have noticed this in your own life. Sometimes this works, but often it doesn't, your willpower doesn't stop you opening the fridge, or avoiding the gym, or buying that item, or returning again and again to your phone to check for what? We can't think or rationalise our way out of our emotions or difficult feeling states. Patients with NEAD are an extreme form of this, however, most people can recognise and accept that we can all suffer from functional symptoms or dissociative processes at different moments in our lives.

#### *Approach to Symptoms and Psychotherapy for NEAD*

Doctors have a different role and remit in working with people with NEAD. They have to be certain that their diagnosis accurately reflects the symptoms, to ensure medication isn't being given that could be harmful or that medication isn't withheld that could be useful.

The journey a person has had through the medical system often has a significant impact on their sense of self. Medics have a symptom based approach which can fragment the person into non-functioning body parts, which are tested (e.g. stroke/epilepsy pathway). The patient has often had a long process to arrive at a diagnosis, typically over a number of years. This often leaves people with the sense that 'if there's nothing physically wrong, then I must be mad.' The diagnosis of NEAD offers less 'legitimacy' and more of a sense of shame as our society stigmatises the psychological and often creates significant hardship as many patients are no longer able to claim benefits following a diagnosis of NEAD. Our approach is aiming to build a more helpful cohesive mind/body awareness, which aims to integrate the whole person and build a collaborative formulation.

Psychotherapists tend to think of patients with NEAD in different ways from Doctors. Freed from the need to be certain we have the chance to be curious with the patient. Therapists can view symptoms as a metaphor which could be quite straight forward, for example, a patient who has one eye that keeps closing because they can't bear to see what has happened in their life. Equally, they can be a starting point to understand how an individual's life experiences and social context might be played out in their symptoms. In light of this we might work with a patient to think about and try to understand the following questions in relation to their symptoms:

When seizures happen? what purpose they might be serving?  
Is it to avoid certain emotions/feelings/situations?  
Is it a trauma response e.g. a dissociative response to triggers in the environment?  
Is it the only way they are able to rest or stop?  
What situations, behaviours, patterns of relating perpetuate the seizures?  
What strategies help to calm and soothe the body/mind system?

Overall I would aim to be a co-detective with the patient; to help them make sense of the symptoms in the context of their life story and experiences. I would treat each case individually. I would aim to have curiosity about their life, asking a lot of questions. This is particularly important if the patient says the seizures 'happen out of the blue'. In the general population most people can acknowledge difficult everyday stressors. This patient group tend to avoid difficult feelings and downplay events others would acknowledge as hard. I would link strategies such as grounding and stabilisation to actual bodily sensations they experience in the therapy room. I would encourage patients to start to notice what is happening in their bodies, moment by moment. In particular, in response to discussing difficult events. This would be carefully graded so that a person might be encouraged to notice their body sensations as

a result being delayed in traffic on the way to a session and then build to noticing sensations in response to ever more challenging situations.

### Relevance of trauma

Patients are helped to understand the impact of trauma on the brain and body with the aim of enabling people to make sense of the legacy life events has left, and that 'it's not their fault', this is how our evolved brains have learned to survive complex traumatic events. This is even more important but more challenging when there has been emotional neglect or conditional love. Often, in these instances, trauma is denied or more accurately out of awareness. Traumatic experiences whether they are clearly identified or more hidden lead to emotional dysregulation. The nervous system becomes on high alert for another threat and this can cause multiple difficulties both physiologically and in anxiety levels.

Some patients become seizure free; some are able to stop some seizures by recognising triggers which may be generated by trauma or relational difficulties. Understanding the purpose the seizures may be serving for each individual is important in working out how best to manage them. If they have a clear trauma history then stabilisation and grounding strategies and support in helping them understand how the trauma experiences are triggering the survival mechanism in the present can be helpful. If the trauma is of a more subtle kind, such as a person who chronically keeps going, is very stoic, puts others needs before their own then, the strategy will be different. The person will need help in recognising the patterns in their life and why those patterns have developed and then need support in starting to try out different ways of being. This can be very challenging for the person as their identity has often been based on them being available for others and their emotional survival has often depended on numbing their feelings.

In these cases, the question that is worth exploring with patients is: What has led them to feel that other people's (concerns, needs, desires) are more important than their own wellbeing? What is often clear is that the family situation either because of illness or relationship difficulties has meant that their emotional and relational needs were not attended to as a child. This leads to the patient devaluing or not noticing what their own needs are. They may feel that they have to 'absent themselves' via a seizure if a feeling that is not acceptable comes up. This is not something in conscious control, but a response to intolerable interpersonal difficulties. For example, a patient who has used physical violence to protect themselves may recognise how destructive this strategy is. The seizure may occur in place of the physical anger. For another individual, the seizure may happen before the person is able to feel any sense of vulnerability or sadness.

### *What makes therapy more likely to work?*

If patient and therapist can find a shared and co-created formulation on what may be causing the seizures then prognosis is better. It is important to emphasise that this is far from a simplistic explanation. The hope is to encourage a nuanced and more reflective way of approaching their symptoms and life experiences rather than to create a fixed and rigid idea of what causes the seizures. Often the work of therapy helps patients to make sense of or understand their diagnosis in the context of their life. This is particularly important if they are chronically disconnected from their feelings or downplay difficult life events. Stability in daily life helps a person to engage more fully in therapy. If they have on-going significant stressors for example financial pressures such as benefit uncertainty, lack of safety such as Domestic Violence or uncertainty about immigration status they will understandably find it harder to engage in therapy.

Recently Alex Calderbank, an MSc Clinical Neurology student, researched outcome measures from our service and found a reduction in symptoms of anxiety, depression and PTSD symptoms and an increase in the quality of life post therapy. We did not explicitly measure seizure rates before and after therapy and are intending to include this in future research, however, patients frequently report a cessation or decrease in seizure frequency post therapy.

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\* A list of the 11 different types of therapy used:

Cognitive Behavioural Therapy (CBT)

Psychodynamic Psychotherapy

Acceptance and Commitment Therapy (ACT)

Compassion Focused Therapy (CFT)

Couples/Relationship Therapy

Eye Movement Desensitisation and Reprocessing (EMDR)

Gestalt Psychotherapy

Integrative Relationship Developmental Psychotherapy

Lifespan Integration

Sensorimotor Psychotherapy

Integrative Arts Psychotherapy

### *Introduction*

This presentation aimed to extend current understandings of NEAD in order to begin to develop a more sociological perspective and to locate the condition in the contemporary social and political landscape. It addressed four areas; NEAD as a contested condition and the differences and similarities between it and other contested conditions; NEAD as a troubling diagnosis to give and to receive and a troubling condition to live with; medicalisation and its reach and limits, and struggles for legitimacy. We then located these in the context of contemporary neoliberal discourses and practices.

In order to illustrate some of our themes, we drew on data from a recent, small study carried out in the north of England, which used repeat free association narrative interviews to explore patients' reflections of living with NEAD.

### *Developing a sociology of NEAD*

Whilst we can draw on concepts within medical sociology (and we do this below) to apply to understandings of NEAD, there are limitations to developing sociological thinking due to the focus of much research around NEAD. In contrast to other, arguably comparable conditions such as chronic pain and depression, there has been little work developing a social epidemiology of NEAD. The recent Goldstein et al (2019) paper begins to attend to this gap and provides demographic and epidemiological data which shows, as with the conditions above, that those with NEAD are disproportionately drawn from socially deprived areas and confirms the already well-established reality that the majority of those experiencing NEAD are women.

A key part of what we wished to raise in this presentation was the extent to which a consideration of the 'outside world' is missing in the bulk of current NEAD research. Where this 'outside world' enters it is as "life events" or as traumas but there is little acknowledgement that rates of negative life events and traumatic experiences have social and classed gradients (Pearlin 2009). Narrowly cognitive models which focus on strategies to manage thinking in response to events largely bracket out the social. This absence of the social is one aspect of what we encountered in the struggles of participants in the study to make sense of and live with their diagnosis.

### *Living with the condition and the limits of explanation*

What marks NEAD out from other contested conditions is that there is a 'gold standard' of diagnosis which establishes beyond doubt that patients do not have an organic or physical basis for their condition. Patients thus cannot challenge the veracity of a diagnosis and are required to engage with explanations for symptoms which go beyond the organic or physical. As trauma or stress-based explanations are most commonly offered by doctors this can be troubling for some. Even those who experience this as congruent with their experiences it may be difficult to understand how stress and trauma translate into seizures. Others may resist what are experienced as psychological explanations as they may feel that they have not experienced stress or trauma. For all patients there is the likelihood of fearing implications of madness or malingering that still go hand-in hand with "mental health" diagnoses. In these circumstances, patients may be left with embodied doubts about the legitimacy of their condition.

In order to understand what may be happening we have applied and reworked the sociological concept of medicalization and the process of entry into the sick role in order to shed light on how NEAD is experienced and lived within the wider socio-political context. In particular, we examined how contemporary neoliberal discourses and practices can serve to drive and shape processes of medicalisation which may transform the clinical encounter into a battleground. What may be happening, we propose, is that this battle is focused around the limits to medical responsibility for NEAD versus the tensions emanating from patient demand for medical legitimization of symptoms (and avoidance of a psychological explanation), sharpened as these are, under contemporary conditions of neoliberalism. By this we mean that there is ambivalence on both sides; historically medicalisation has been presented as an imperialist project with medicine embracing greater areas of human experience. But in the case of some disorders which can broadly characterised as "medically unexplained" there is resistance – and ambivalence - to managing these patients medically (Salmon 2007). There is a corresponding ambivalence amongst patients; medical legitimacy is sought but what is offered is a form of medical

legitimacy but one that is viewed as largely not acceptable since it is framed psychologically, rather than as issue or disordered physiology. To engage the patient has to acquiesce to this formulation.

We also note that there is a paradoxical and ambivalent strand that runs through many aspects of the everyday management of NEAD. Diagnosis, for example, is presented in terms of the absence of physical or organic factors. However, doctors may provide legitimate entry into the sick role and offer medication, all of which serve to construct the problem as “medical”. The outcome from this process may be patient uncertainty – and anxiety - about how to integrate the explanation for symptoms and medical responses – and, of course, narrate these to others. These paradoxical elements seed ambivalence and embodied doubt about their legitimacy as genuine ‘sufferers’. Much of what those living with the condition struggle with is achieving and maintaining legitimacy.

#### *Conclusion; legitimacy and contemporary neoliberalism*

The ambivalence engendered amongst many NEAD patients by the above processes is particularly problematic in the context of the neoliberal construction of subjectivity and the idea of the responsabilized self, (the contemporary hegemonic idea encountered in relation to selfhood, health and wellbeing). Within this wider construct, there is effectively no legitimate space for the ambivalence and embodied doubt that those diagnosed with NEAD often experience. Suffering, particularly the sorts of social suffering described by Bourdieu (1994) where the body is partly able to adapt to world that engenders harm but none the less cannot adapt to suffering completely resulting in bodily expression is not named and is unacknowledged.

In these circumstances, there is much that can be characterised as troubling and difficult about the management of NEAD, both from the point of view of doctors and patients. One potential solution, tentatively proposed here, is to seek to develop a new paradigm to understand NEAD. This would name the social suffering (eg stressors or traumas) that many patients refer to in their biographies, but which are typically framed in psychological language (and which arguably have their roots in wider social processes). We would also suggest that naming the neoliberal processes which sharpen patients’ anxieties about the need for medical legitimation might also be one way forward. This new paradigm might allow doctors and patients to move beyond the reductive Cartesian dualisms of mind and body. We draw on the literature on the sociology of pain to further exemplify our argument.

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## Metaphysics, Epistemology and Ontology – Annamaria Carusi

Non-epileptic attack disorder or NEAD is a condition identified by negatives. It is not epilepsy. It is not medically explained. The two negatives are closely inter-related: When something is medically unexplained its existence is called into question. Either it exists only in the nebulous realm of the 'non', defined relative to the things that do have real existence, in a kind of conditional tolerance presumably until such time as a thing is found for it positively to be. Or it simply does not exist, really. Small wonder that patients receive this diagnosis defensively: are they being accused, through convoluted terminology, of 'making it up'? Doctors face the difficult task of explaining to patients that what they are suffering from is medically unexplainable; and from this it is frequently understood that its reality, as a medical condition, is questionable. Epistemology and metaphysics are contested grounds in these doctor-patient interactions, and with them, the biomedical model that underpins the worldview assumed in them.

The traditional (at least to modern Western medicine) biomedical model assumes one of two forms of metaphysics: a form of physicalist monism or materialism that claims that fundamentally only material entities exist, or a form of dualism that claims that there are two kinds of entities, material and immaterial, between which it sharply distinguishes. Descartes' dualism, we must remember, was formulated against the background of the rising power of science to explain the world. As a response it contained both a concession of the material things to science, and a retention of the immaterial things for philosophy and theology. It amounts to a divvying up of entities in a great disciplinary cleavage, which has irrevocably shaped what and how we believe we know. Thus, the biomedical model can comfortably take either of these forms, and if dualism is assumed, focus its attention on the material side of things, without necessarily committing itself to the view that this is all there is. Following on from this metaphysics, to the question of what makes something a disease rather than anything else — the ontology of disease — the biomedical model will tend to respond that disease is defined by something that is materially instantiated: that is, something in biology, in physiology. This has the added benefit of seeming to place the epistemology of medicine on the firm ground of science, and of being a matter of what can be objectively known. This in turn goes along very well with a certain account of explanation: that is, that explaining a phenomenon (such as disease) scientifically, consists in identifying its cause, or failing that, since so often there is no single ultimate cause, or we do not know what it is, the mechanisms that give rise to it.

The biomedical model clarifies why something like NEAD will be metaphysically problematic: on a materialist or physicalist view, it has no material instantiation in biology or physiology and is therefore not real. On a dualist metaphysics, it may be real, but it has the wrong kind of reality for it to be a bona fide medical matter, as its hypothesised roots in trauma place it on the immaterial side of things. It therefore does not count as a 'real' disease, if by disease is meant something that can be traced to biology or physiology somehow 'gone wrong'. And since it cannot be so traced, it is also medically unexplained.

The biomedical model is not the province of doctors alone. Patients very often assume a form of it too, and for this reason may experience their diagnosis as a denial of the reality of their condition. The biomedical model is culturally and socially entrenched, and is at play in typical doctor-patient interactions where there is a demand for a name, for something physical, real and not 'made up'; and for a treatment, a drug to put right what is (materially) wrong, from the medical establishment.

We shouldn't think, however, that the biomedical model is essential or inevitable to modern medicine. Even though something along the lines of the metaphysical and epistemological model I have sketched out is the one most likely to be articulated in explicit communications, something different may be tacitly in the background, more difficult to articulate, especially in propositional form, but that finds expression in different ways. Our challenge is to find the indirect means to surface these different metaphysics and epistemologies, that do not run along the expected channels but break off into different ways of thinking, that allow for more complex inter-relationships between material and immaterial things, and that perhaps allow to think of bodies, minds and environments, not as discrete entities defined independently of each other, but as complexly intertwined and intra-dependent. Or not: we do not know what we may find unless we are ingenious enough to learn to listen for different

medical metaphysics and epistemologies. NEAD may be just one of these modes of speaking that highlights the need for a different way of listening.

Suggested Reading

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## Towards a Recovery Approach in Mental Health - Pat Bracken

In my contribution I contrasted the current technological understanding of mental health with what is called the 'recovery approach'. Most of my talk was concerned with making a conceptual and empirical critique of the technological approach.

### *The technological Paradigm<sup>1</sup>*

By the technological paradigm in psychiatry, I mean an approach to understanding experiences such as low mood, hearing voices, suicidality, self-harm, fearfulness, elation that sees them *primarily* as technical problems that need fixing, just as we would problems with our kidneys, or our livers, or our washing machines or our cars

The technological approach works with the following assumptions:

- The problem to be addressed has to do with a faulty *mechanism or process* of some sort
- The mechanism or process can be *modelled in causal terms*, ie described in a way that is universal, a way that works regardless of the context [example of measles and depression]
- Technological interventions are *instrumental*. They have nothing to do with opinions, values, relationships or priorities.

In psychiatry, we see the technological paradigm shaping what have arguably been our three central concerns over the past 25 years:

- classification systems (DSM etc),
- the search for causal processes (biological and psychological) in mental disorders and
- the application of the 'evidenced based medicine' approach in relation to interventions.

A key move of the technological approach is to push the non-technical, non-specific, aspects of mental health care to the margins. The technical approach does not ignore questions of relationships, values and meanings but it sees them as *secondary* issues.

### *The Recovery approach*

The recovery movement grew out of, what we have come to call, 'the service user or consumer movement'.

A number of people who had been informed that they were suffering from life-long psychiatric conditions (such as schizophrenia) managed to find paths that led them to a reality of personal recovery. They then wrote about their journeys in an attempt to provide inspiration for others. While some of these paths involved mental health services, most did not. Some reported that traditional mental health services had worked to impede their personal recovery and some reported that they had been damaged by the way psychiatry framed their problems and intervened in their lives.

The recovery literature moves the discussion about mental problems away from the clinical and technical focus on issues such as diagnosis, assessment, classification, prognosis and treatment. As Repper and Perkins put it:

'Recovery is not about "getting rid" of problems. It is about seeing people beyond their problems – their abilities, possibilities, interests and dreams – and recovering the social roles and relationships that give life value and meaning'<sup>2</sup>

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<sup>1</sup> Bracken, P., Thomas, P., Timimi, S., Asen, E., Behr, G., Beuster, C., . . . Yeomans, D. (2012). Psychiatry beyond the current paradigm. *British Journal of Psychiatry*, 201(6), 430-434.

doi:10.1192/bjp.bp.112.109447

<sup>2</sup> Repper, J, Perkins, R. (2003) *Social Inclusion and Recovery*. London: Balliere Tindall, p. ix

In the literature of recovery we are into a language of 'social roles, relationships, values and meanings'. However, we define 'recovery', this approach involves the profound realisation that these issues are *not secondary*. They are actually the most important, the central issues facing people with mental health problems.

### *Challenges to the Technological paradigm*

#### *Conceptual analysis*

At the heart of the technological paradigm is the idea that the 'mind' can be conceived of a thing. It is something that can be studied with the same tools we use to study and understand other 'things' in the world.

-The dominant view at present we might call *biological reductionism* but *cognitive psychology* also fits with the technological approach

A fundamental assumption of both is that the elements of psychological life can be characterised in causal terms, so that hypotheses can be generated and then used to predict behaviour under different circumstances.

While this is now a sort of 'common-sense' account and is certainly the assumption that modern psychiatry is premised upon, the tradition of phenomenology has presented serious challenges over the last 100 years.

#### *Being-in-the-world*

The way in which our human bodies are made anatomically and physiologically means that a certain kind of world opens up for us. We have a certain way of hearing, seeing, smelling the world, a certain way of experiencing space and time. In a very real way, we *bring* color and sound to the world. Our particular contribution to this world that we live in becomes clear when we try to imagine what sort of world opens up for a fruit fly, or a fish or a bat.

We are simply not 'in' a world that is separate from us.

The philosopher Heidegger used the composite term *being-in -the- world* in an attempt to get over this and to conjure up what reality is actually like for us most of the time<sup>3</sup>.

But the way in which a world opens up for us is not just dependent on our anatomy and physiology. A human world only becomes possible for us because we live in a world with other people and in the midst of a culture and a language. Therefore, the opening up of a world is never an individual act.

When I look at a flower and see it as red and beautiful, I can do so only because my human physiology allows me to see a certain part of the electromagnetic spectrum and make contrasts with other colours. But it is also because I have the idea of a flower and the notion of beauty available to me.

I experience the world with words, beliefs, emotions and patterns of thought that come from the social world in which I live. And this social world in which I emerged and learned how to be was derived historically from another social world that came before it, stretching right back to when humans first used words and symbols

In human existence, matter becomes aware of itself and tries to understand itself. We think about time and its passing. We are aware of our own death and thus the passing of the world. As far as we are aware, humans are the only beings on this planet who are open in this way. Not only does a world show up for us but we are aware of our role in this.

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<sup>3</sup> Heidegger M. (1962) *Being and Time* (translated by J. Macquarrie and E. Robinson). Oxford: Blackwell.

If we treat human reality as simply another thing in the world, and neglect this 'world-disclosing' aspect of what we are, we are actually missing the most important dimension of our being

### *Meaning and intelligibility*

The world that opens up for us through this extraordinary coming together of matter physiology and culture, of matter and symbol is *intelligible*. It appears as meaningful to us. For the most part we take this for granted. Like the air we breathe, we don't notice it.

But where does it come from? How does meaning come into our lives, into our worlds?

For Heidegger we are always, already orientated to our worlds before we become aware of thinking. This pre-cognitive, pre-reflexive orientation to the world comes about through our physiology and our immersion in a social world and it gives us a sort of pre-understanding of the world. The world is intelligible to us before we think about it. It is meaningful for us before we engage cognitively with it through detached thought. Indeed, this pre-understanding of the world provides the ground upon which we engage with the world through reflection and analysis.

But this ground is not a set of cognitions, or schemata, or propositions

It is not really cognitive in nature, it is also affective and most importantly it is structured by the simple fact that the world matters to us, we *care* about it [not in the sense of worrying about things but simply that it matters to us]

Thus, I am in a world of meaning before I even start to think about it

So, a phenomenological position argues that

- there is no mind that can be separated from its world
- human reality is world-disclosing, through it the things of the world show up and are meaningful, but this reality is not itself 'a thing'
- human reality involves a 'pre-understanding' of the world that cannot be grasped definitively
- the intelligibility of the world emerges from our embodied, engaged involvement with the social, historical and cultural context that we emerge in and live our lives through

One last point from this relates to the question of 'naturalism', the idea that we will be able to explain the life-world, the meaningful world of human experience by way of the natural sciences

### *Heidegger's critique of naturalism and scientific reductionism*

We primarily encounter the natural world in what Heidegger called 'available forms': iron tools, wood tables, steel knives, mashed potatoes. In this way natural objects form part of our human environment and are useful, beautiful, tasty. But for the scientist, water (for example) shows up as atoms of hydrogen and oxygen. It has certain physical properties. It is not experienced by the scientist as refreshing, or beautiful.

The scientific understanding of the natural world only emerges when we systematically strip out such qualities. This process 'produces' a nature that is understood in causal terms, in terms that we can analyze as a set of processes.

But the world we live in everyday is primary. This is a world that is saturated with significance for us. It is out of this world that we reach to create science. What is at stake here is the *primacy* of the life-world. The scientific way of engaging with the world emerges from this.

As we produce the natural sciences through a process of stripping the life-world of its value, significance for us, it seems implausible that we will be able to use the tools of the natural sciences to explain that very life world.

### *Empirical Evidence*

In recent years, the results of decades of biological research in psychiatry have started to accumulate. There is a growing consensus that they add little to our understanding of mental illness and have contributed almost nothing to clinical care

In a book, published this year, Anne Harrington, Professor of the History of Science at Harvard, gives a comprehensive account of psychiatry's search for the biology of mental illness. Her conclusions are damning. The history of psychiatry is characterised by

'self-serving declarations of imminent breakthroughs and revolutions'<sup>4</sup>

What about the evidence from our treatments: do they not work by fixing biological faults or blocks to cognitive processing?

And actually, yes, most of the treatments we use seem to have benefits for people.

For example, when it comes to depression:

About 2/3 of people who take antidepressants feel better, for a while anyway. Most people who engage in psychotherapy feel that they get something from it. This is not in question.

However, the empirical science is telling us that *most* of our interventions for depression (pharmacological, psychotherapeutic and even ECT) actually work, not by fixing faulty processes but by generating hope, expectation, solidarity and trust.

For example, it is now clear that *most* of the therapeutic benefit of anti-depressant drugs in drug trials is due to the placebo effect.

How does the placebo effect work: we are essentially looking at non-technical factors: relationships and meanings. When it comes to anti-depressants, the 'fixing the chemical imbalance' story simply doesn't correspond to reality. The placebo effect, based on relationships, trust, meaning is where the real action lies.

Similar conclusions emerge with psychotherapy. Therapy works. But, it doesn't seem to matter very much what model or what specific techniques are used. What really matters is the quality of the relationship between patient and therapist, whether the patient feels respected and valued, whether the encounter is meaningful.

What emerges from the literature on treatments for depression is the key importance of relationships and meanings and values. Getting these right is where the 'action is', these are the elements of our encounters that matter. What technology we use is not irrelevant but it is of *secondary* importance.

What about cognitive psychology? Does this receive validation through the efficacy of CBT?

Actually, no. Not for depression anyway.

The 2010 NICE Guidelines identified 'no clinically important differences' between CBT, interpersonal psychotherapy (IPT), short-term psychodynamic psychotherapy and brief supportive counselling, behavioural activation or GP treatment as usual when it compared the evidence for psychotherapeutic treatments of depression (NICE 2010, p234-235).

A number of studies have contradicted Beck's original idea that work on cognitive structures or core schema was essential for therapeutic change.

'little evidence that specific cognitive interventions significantly increase the effectiveness of the therapy'<sup>5</sup>.

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<sup>4</sup> Harrington A. (2019) *Mind Fixers. Psychiatry's Troubled Search for the Biology of Mental Illness*. New York: W.W. Norton. Page 276.

<sup>5</sup> Longmore, RJ, Worrell, M. Do we need to challenge thoughts in cognitive behaviour therapy? *Clin Psychol Rev* 2007; 27: 173–87.

### *Conclusion*

I've made the case that the assumptions that underlie the technological approach in psychiatry are not justified when it comes to psychiatry: the territory of *mental* disorders

-the characterisation of the mind as a thing and mental symptoms emerging from faulty biological or mental processes does not do justice to who we are as human beings. This approach misses the world-disclosing dimension of our being which is probably the most characteristically human things about us

-the project of biological reductionism has simply not delivered in mental health. It doesn't work!

-The evidence in favour of a specifically 'cognitive' approach in psychotherapy is not strong

-what seems to be important for recovery is hope, solidarity, finding meaning and these can come from different sources, primarily from the 'lived world'

## Bill Noble

This workshop was an excellent opportunity to consider NEAD from a number of diverse perspectives including general practice, neurology, psychotherapy, public health, sociology, philosophy, psychiatry and service users. A multidimensional model of a condition emerged with an aetiology related to previous life trauma. Other factors conveying risk for this condition are unknown. The mechanism for NEAD is also not known at a pathophysiological, cellular or a molecular level.

We are left with the theory that trauma prompts unpredictable, involuntary changes in behaviour that are qualitatively different from epilepsy in their manifestation and origin. The only postulate from discussion was the possible role of the autonomic nervous system in some kind of protective adaptation to distress prompted by psychological triggers.

The lack of a comprehensive medical understanding of NEAD has adverse consequences for people with the condition. The sociologists note that without a medical diagnostic category other than somatization, sufferers are denied the validity that society requires to accommodate their disability. Clinicians are left with a nuanced diagnosis that requires a prodigious professional relationship to attempt an explanation. Only unproven interventions to mitigate the effect of previous trauma are available.

The palliative medicine perspective recognises the impact of genetics, pathophysiology, family history, life history, comorbidities and current stressors on the aetiology and expression of any condition. We use multidimensional therapeutic interventions for conditions that have no definitive treatment. We have recently engaged with a movement that promotes "Compassionate Communities" to promote care of the dying and bereaved in a similar way to the "Recovery Movement".

The name, definition and diagnostic criteria for NEAD were contested, hampering research. The current psychosomatic model, without defined epidemiological risk factors or genetic targets is unlikely to attract research funds from the pharmaceutical industry. Academics are wary of entering a field of research where service users are looking for evidence that could validate their experience. Studies to identify other factors conveying vulnerability to the condition are likely to be attacked if negative and we still lack data on what kind of trauma causes NEAD in an individual, rather than post-traumatic stress disorder, personality disorder or chronic anxiety.

Common conditions known to have significant psychosomatic causes are only open to other therapeutic interventions when the various triggers and mechanisms are understood. At medical school, I was trained to believe that work stress caused duodenal ulcers and migraine but that personality type caused myocardial infarction and possibly prostate cancer. This might still be true, but triple therapy, triptans, thrombolysis and microsurgery have helped considerably.

I have seen NEAD patients with disorders of the autonomic nervous system including migraine, functional bowel and bladder disorders, postural orthostatic tachycardia syndrome as well as childhood trauma. Studies are emerging, suggesting that NEAD may be associated with migraine. I would suggest a systematic review and a cohort study to identify psychological factors, comorbidities and familial conditions to help sufferers find a more comprehensive explanation of their condition as a first step.

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Consultant Physician in Palliative Medicine Sheffield Teaching Hospitals  
Honorary Professor of Community Palliative Care*

## Hilda Reilly

My interest in NEAD stems from my research on two patients from the early history of psychoanalysis, Bertha Pappenheim, ('Anna O'), and Anna von Lieben, ('Cäcilie M') (Breuer and Freud, 1974). Both patients were diagnosed as suffering from hysteria. Their symptoms included convulsions, absence states, hallucinations and diverse sensory and speech disturbances.

Freud believed that hysterical symptoms were produced when an individual had been unable to express an appropriate emotional reaction at the time of a previous negative experience and that the psychic energy of this repressed emotional reaction was subsequently discharged into the formation of a physical condition.

Neurologists Ferguson *et al.* (2006) hypothesise that the anatomical structures of the temporal lobe function in a way which correspond to Freud's tripartite structure of the mind (unconscious, preconscious and conscious). According to Freudian theory, repressed ideas are prevented from becoming conscious by the preconscious which acts as a censor, only reaching consciousness when the censor is relaxed, as, for example, in dream states. Ferguson *et al.* suggest that this censoring action can also be inhibited by both temporo limbic seizure discharge and by electrical brain stimulation.

In discussing the phenomenology of seizures, they describe cases where patients relive a past experience with all the original accompanying emotions; patients who engage in uncharacteristic behaviour due to the unblocking of suppressed feelings – which Ferguson *et al.* interpret as the censor breaking down and the 'id' being allowed to dominate; and perceptual changes which can occur in the visual and auditory spheres.

In reading Ferguson *et al.* I am struck by the parallels with the symptomatology of Pappenheim and von Lieben and I ask myself how is it that Pappenheim, for example, could experience macropsia and prosopagnosia if not through some aberrant neurological activity. Those are not, after all, common conditions which she could have been feigning. It is extremely unlikely that she would even have heard of them.

In the non-dualist paradigm, all mental events – whether cognitive, emotional or sensorial – are associated with neurophysiological substrates and yet the medical discourse does not reflect this. Certain medical conditions are described as being 'psychosomatic', or 'all in the mind', as if sufferers were the willing agents of their own misfortune. In an egregious example of editorial tactlessness, a recent book on the subject, written by a neurologist, is titled *It's All in Your Head: True Stories of Imaginary Illness*. The reason for this may lie partly in the fact that there is still no satisfactory solution to David Chalmers' 'hard problem' of consciousness – how it is that physical processes can give rise to *qualia*, to subjective experience. For want of a better explanation, we fall back, even if unconsciously, on the *res extensa* of Descartes, the 'ghost in the machine', which has the body do its bidding.

Ferguson *et al.* claim that they may have found the brain-mind interface. I am not so sure. I think it is more likely to be found in whatever it is that gives rise to 'hysterical' symptoms.

*Hilda Reilly, PhD student, The University of Glasgow*

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## Alistair Wardrope

What is non-epileptic attack disorder (NEAD)? It is, if nothing else, a diagnosis, a term individuating certain human bodily phenomena and subjective experiences as constituting a distinct disease entity. So we can rephrase our question: what are we doing when we view such phenomena through the lens of a biomedical model?

With the question re-framed thus, we can approach it at several different levels. Most broadly, we can study NEAD *qua* scientific model. What kinds of thing are scientific models? They are representations of natural phenomena; but they need not be exact (think of the simple harmonic oscillator as representation of a pendulum), or compatible with other useful models of the same phenomenon (the liquid drop and shell models of the atomic nucleus are both important in nuclear physics, yet entirely incompatible), or indeed even internally consistent with the theories they invoke (the Bohr and Rutherford models of the atom famously lack this property). Scientific models are pragmatic tools, used to represent phenomena in certain respects, for certain purposes.<sup>1</sup>

We may then ask: what is NEAD, *qua* medical model? If medical models are scientific models, and scientific models are perspectival and pragmatic representations that describe certain aspects of phenomena, in certain respects, for certain purposes, what aspects of human phenomena do medical models seek to describe, and to what ends? In answering this type of question, we might seek to explore how medical taxonomies are created and evolve. On closer examination, even non-troubling, uncontroversially 'organic' pathologies like the myocardial infarction (MI, 'heart attack') turn out to have unstable, evolving definitions. The identification of the 'heart attack' as a distinct pathology, and its classification into different types, has depended upon the technologies used to describe it (from autopsy, through the electrocardiogram (ECG) and angiography, to serum biomarkers and echocardiography), and to treat it (whether medically, surgically, or radiologically).<sup>2</sup> This suggests that, to understand NEAD, we must also interrogate the perspective, purposes, and tools of medicine, and their role in shaping medical models of human experience.

Only now do we come to the question of what is NEAD, *qua* itself. If NEAD is a "troubling illness" or contested diagnosis, then it is presumably because, as a model of human experience, it is somehow different from uncontroversial diagnoses such as MI. But if the above is correct, this cannot be because the NEAD model fails to describe everything that can usefully be said about its target phenomena, or that other (perhaps incompatible) models of the same phenomena may also be useful – for that is true of models throughout the sciences. Nor can it be because the individuation of NEAD as a distinct entity depends on the technologies available to and interests of health workers and researchers – for that is true of non-contested diagnoses too. What remains? We may ask whether NEAD is a good medical model, judged internally to the standards of medicine – does it serve to predict prognosis, to guide treatment, to aid recovery? Or we may ask whether NEAD is even a 'medical' model at all – do the perspective and purposes of the NEAD model differ from those used in other biomedical models of disease? The importance to clinicians and patients with 'medically-unexplained symptoms' of 'acceptability' of the explanation afforded by the model – and the potential therapeutic role of the explanation alone<sup>3</sup> – suggests one important disanalogy with other diagnoses (the cardiologist is less concerned with how 'acceptable' a patient finds their explanation of MI).

Moving from general to specific, this analysis suggests that we must answer some general questions about biomedical models and scientific model construction before providing a satisfactory answer to our original question, "what is NEAD?" But moving from specific to general, we may also inquire: if NEAD is a 'troubling illness', how much of that is because it serves as a test case that forces us to explore the limits of what medicine, or science, can or should describe?

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## References

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2. Howell JD. Coronary Heart Disease and Heart Attacks, 1912–2010. *Medical History*. 2011;55(3):307-312. doi:10.1017/S0025727300005317

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## Summary and Further Work – Jon M Dickson

It is implicit in the term non-epileptic attack disorder (a type of medically unexplained symptom) that doctors have been unable to provide a satisfactory explanation for the condition, the diagnosis emphasizes what NEAD is not, and not what it is. This statement is not a criticism of the individuals involved in the work so far, much NEAD research is high quality and is driven by compassion for the people affected. But the bio-medical approach to illness is built on a philosophical framework which tacitly excludes many potential explanations for NEAD. Other disciplines outside of medicine, as well as patients and the public, adopt alternative metaphysical, epistemological and ontological positions which offer the potential for new ways of understanding it.

The medical literature and medical practice tends to focus on the individual, but the literature on trauma and the etiology of NEAD shows unequivocally that much about this condition can only be understood by thinking of relationships between individuals, of families, of society and of culture. But a sociological perspective on NEAD is currently missing from the medical literature on NEAD. Psychotherapy is the only effective treatment for NEAD and most schools of psychotherapy emphasise the importance of relationships (social factors) and invoke metaphysical positions which are arguably not consistent with modern medicine or at least emphasise concepts which medicine considers secondary such as inner knowing, the soul and meaning. As with doctors, the philosophical beliefs of sociologists and psychotherapists are often tacit and built-in to their disciplines, and not subject to rigorous philosophical analysis. So like doctors, they need advice and guidance to think philosophically and to state the philosophical position that informs their practice.

What emerged from the discussions in the workshop was a plurality of philosophical commitments amongst the group. I believe that this plurality is to be welcomed, for future work it means not battling to find a single philosophical position which is right or wrong but acknowledging that different ways of thinking are deeply held by individuals (professionals and patients). These ways of thinking should be characterised, scrutinised and their potential to contribute to understanding of NEAD evaluated. During our discussions we found that different philosophies can be useful in different situations and it may be useful to think of a 'philosophical toolbox' for NEAD where diagnosis, for example, and the assumptions built into that concept, are helpful at some times and at other times are unimportant and even damaging.

The potential for an inter-disciplinary collaborative project to study NEAD, involving the humanities and the natural sciences, especially medicine, known together as the medical humanities, was the main conclusion from the workshop. We sketched a number of potential research questions which are listed in the Appendix. I have included them in this document to ensure a full record of the workshop but they are intended as notes to stimulate our ongoing work and not as a definitive record or plan.

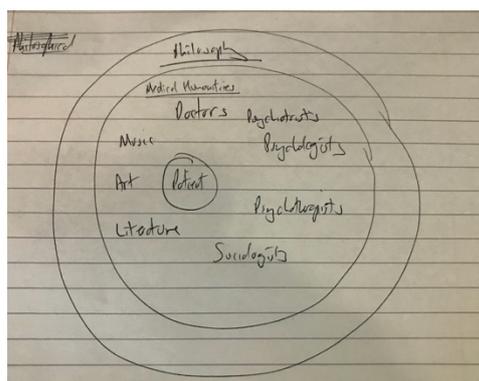


Figure 1. A conceptualization of philosophy, the medical humanities and NEAD. The diagram is intended to emphasise the importance of philosophy and its foundational position in most disciplines whilst acknowledging that philosophers have commitments that are open to question and could themselves be actors in the inner circle.

Appendix - Future Research - JMD

**1) Aim/questions:** ‘Map’ the philosophical positions of professionals (doctors, sociologists, therapists) and patients to establish the full range of possible views and to discover which dominate. Is there philosophical pluralism amongst these groups? Does one philosophical position prevail? Figure 2 is an imperfect sketch of a map created by JMD, in the proposed research the map would not be predetermined but would be created during the research project. Figure 3 is from AC and presents another conceptualisation of the ‘map’. **Methods:** create a philosophical framework, interviews using discourse analysis to reiterate the framework and to ‘locate’ interviewees on the map.

**2) Aim/questions:** Patient and public involvement (PPI) in this work.

**3) Aim/questions:** What is the social epidemiology of NEAD? Parallels with depression and pain literature. **Methods:** Initially systematic review, then retrospective/prospective study (quant: identify data sources, qual: interviews).

**4) Aim/questions:** What are patients views of successful recovery from NEAD after psychotherapy? What was the significance of the diagnosis? What was the significance of specific therapeutic techniques? Was recovery based on relationship with the therapist regardless of modality? **Methods:** qual: interviews.

**5) Aim/questions:** What would a recovery approach for NEAD look like (perhaps include Open Dialogue project methods)? How could this be delivered in the NHS? **Methods:** scoping, discussion with psychotherapists, review of current methods, implementation in Sheffield.

**6) Aim/questions:** What is the story (narrative) of people with NEAD? Is trauma the only relevant etiological factor?

**7) Aim/questions:** Who might fund the above? NIHR (probably not), ESRC, Wellcome, others?

**8) Aim/questions:** Who might publish this type of work? Inter-disciplinary work often doesn’t have a natural ‘home’ in single discipline journals eg sociological papers in neurology journals. Need to identify journals and other platforms.

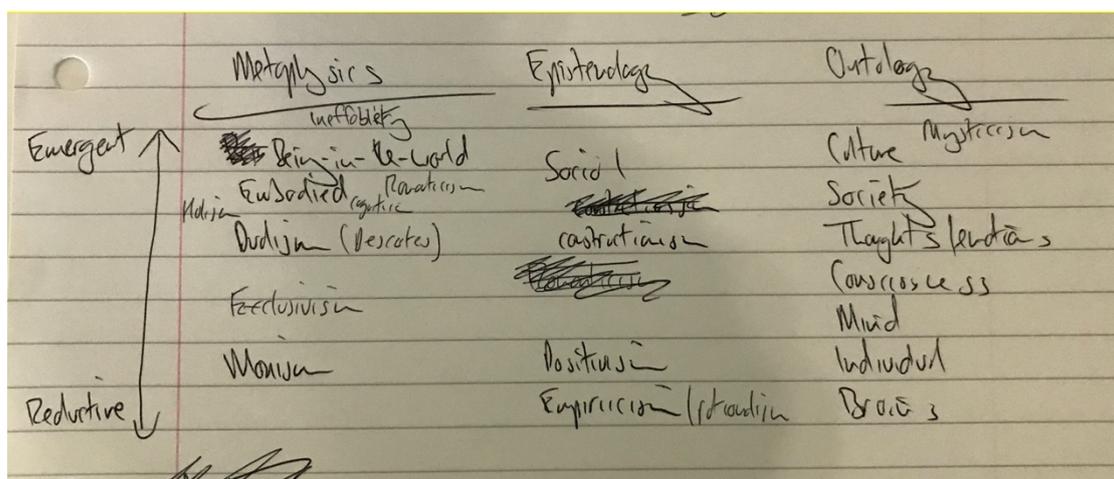


Figure 2 An initial sketch of a philosophical ‘map’ (or framework) drawn by JMD which shows the main philosophical positions relevant to explanations of NEAD.

# Biomedical / humanistic model

In anticipation of potential troubles ahead ....

**Table 1** Comparison of metaphysical, epistemological, and ethical boundaries of the biomedical and humanistic models of western medical knowledge and practice

	Metaphysics	Epistemology	Ethics
Biomedical model	Mechanistic monism	Objective knowledge	Emotionally detached concern
Humanistic models	Dualism/holism	Subjective knowledge	Empathic care

Marcum 2008: 13

Carefully consider where disease/ illness/ phenomenology and narrative might fit  
Do they disturb this distinction between models?

Figure 3 Marcum's 'map' with a commentary on its potential weaknesses by AC.