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Letter

A NEAD for change? Clinician attitudes towards non-epileptic attack disorder

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Keywords
Clinical neurology, Functional neurological disorder, Liaison psychiatry, Neuropsychiatry, Systematic review

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Non-epileptic attacks (also called psychogenic non-epileptic (PNES), functional or dissociative seizures) present similarly to epileptic seizures but without ictal electroencephalographic (EEG) discharges. Non-epileptic attack disorder (NEAD) is classified as a conversion disorder in DSM-5 and a dissociative neurological symptom disorder in ICD-11. It is often associated with long-term disability. People with NEAD access healthcare in a variety of settings and frequently report negative experiences,[1] which often relate to fragmented care and negative clinician attitudes towards NEAD.

To explore current understanding of clinician attitudes towards NEAD, we conducted a systematic literature review,[2] which was registered on PROSPERO and adhered to PRISMA 2020 guidelines. Three electronic databases were searched using search terms developed with an academic librarian. Studies reporting general attitudes and beliefs of clinicians regarding NEAD in adults, published in the past 10 years, were included. Data were extracted from each study with a predesigned proforma, using the Mixed Methods Appraisal Tool[3] to assess study quality and bias.

In total, 508 citations were identified, of which 80 were selected for possible inclusion. Citation searching identified 12 additional studies; in total, 24 studies met inclusion criteria. These studies spanned nine countries (Brazil, Canada, China, France, Iran, Namibia, South Africa, UK, USA), with two global studies. Sixteen studies collected data via questionnaires, and eight used interviews. The main healthcare professionals (HCP) included were psychiatrists, neurologists, general practitioners and emergency medicine practitioners.

Thematic analysis identified seven key themes: terminology; aetiology and comorbidities; confidence in diagnosis and training; views on optimal management; communication regarding diagnosis and treatment; systemic challenges and international differences; and differences among HCP.

Across the nine papers assessing terminology, the term most widely used was 'PNES'. Overall, nine different terms were described; these included 'pseudoseizures', 'NEAD', 'functional seizures' and 'hysteria'. Terms for individual episodes included 'seizures', 'events' and 'attacks'. Some clinicians noted that terms including 'psychogenic' or 'pseudo' might be alienating owing to the implication of a non-medical disorder.[4] The data also highlighted that 'non-epileptic' could be perceived negatively, as a 'non-diagnosis'.[5] Standardising language could improve recognition, communication and service development and reduce stigma.

Perceptions regarding the aetiology of NEAD and common comorbidities were investigated in 22 studies. Clinicians reported that NEAD commonly co-occurred with psychiatric conditions (notably anxiety, depression, personality disorder and post-traumatic stress disorder) and 'physical' causes including epilepsy, head trauma and brain lesions. Clinicians generally agreed that NEAD had 'psychological' rather than 'organic' aetiology. The most common aetiological factors described were psychiatric conditions, childhood psychological trauma and response to stress. In a 2016 French study of 963 psychiatrists, 45% believed that PNES could be caused by 'a need to seek attention'.[6] A minority of participants across the studies described 'malingering' or 'faking' as a cause for NEAD.

Sixteen studies explored confidence in diagnosis and training relating to NEAD, with epileptologists expressing the greatest confidence in diagnosis. Many described difficulties in differentiating NEAD from epilepsy; this was often attributed to lack of training. In one study, 25% of psychiatrists reported receiving specific training regarding NEAD.[6] There was consensus among clinicians that additional training regarding NEAD is required; this could be important for both improving patient experience and reducing stigma.[4]

Fourteen of the included studies explored beliefs regarding management approaches in NEAD. Clinicians consistently agreed that psychological therapy was the most effective treatment, and that anti-epileptic drugs were rarely indicated. Nevertheless, 30% of clinicians in one study said they would prescribe anti-epileptic drugs in NEAD in some cases.[7] In another study, 79% of HCP reported that most patients were prescribed antidepressants and that 60% received psychological therapy.[8] There is therefore a mismatch between optimal management of NEAD and real-world clinical practice. This may well stem from diagnostic uncertainty leading to precautionary treatment, and a lack of access to appropriate and timely diagnostic investigations and psychological therapies.

In the 14 studies exploring communication of NEAD diagnosis and treatment, clinicians consistently viewed neurologists as being the best positioned to do this. Neurologists were generally the most confident in their self-reported knowledge and training around NEAD. Clinicians highlighted the importance of communicating the diagnosis with a friend or relative present for support and clearly explaining the rationale for the diagnosis and treatment options, including referral for psychological or psychiatric support.

Systemic challenges and international differences were explored in 14 studies. Globally, poor awareness of NEAD and timely specialist assessment were highlighted as challenges affecting patient care. Lack of resources (including EEGs and specialist services) and discrepancies between privately and publicly funded healthcare within some countries were major challenges. In general, there were greater challenges with physical resource in the global South, whereas waiting lists and appropriateness of referrals were more often described in the global North.

Seven studies explored attitudes towards NEAD in more than one group of HCP. Generally, HCP held negative attitudes towards NEAD, with common themes being high use of resources and complexity and fragmentation of diagnosis and care. There were no clear differences between groups, and one US-based study found that these views were independent of staff gender, age, profession and department.[9] Several authors posited that negative attitudes towards NEAD related to HCP feeling frustrated and anxious about their own level of competence and the lack of resources for diagnosis and care.

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There is a prevailing ambivalence in clinician attitudes towards NEAD that is unhelpful for patients. Given that clinicians describe a lack of adequate training in diagnosis and management, as well as insufficient access to diagnostic resources and meaningful multispecialty working, it is incumbent upon both clinicians and those in leadership roles to ensure that systemic issues are addressed. The lack of this infrastructure means that an already vulnerable patient group, who have often experienced trauma and/or psychiatric illness, are further disadvantaged by the care system.

We highlight a clear need for clinical training, structured guidelines, standardisation of terminology, improved interdisciplinary working and access to resources for diagnosis and management to achieve better outcomes for people experiencing NEAD. Many such changes are possible even within resource-constrained healthcare systems.

Declaration of interest

J.R. and S.S. are members of the editorial board of the *British Journal of Psychiatry*. Neither took part in the review or decision-making process for this paper. The data in this letter have been presented at the recent International Congress of the Royal College of Psychiatrists.

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Author contributions

AA completed literature searches, reference list screening and data extraction and co-wrote the manuscript JF contributed to data extraction and interpretation and co-wrote the manuscript SS Supported development of the idea and methods for the review, contributed to study selection, interpretation of data and contributed to writing the final manuscript JR conceptualised the study, supervised literature searches, screened papers, reviewed data extraction and co-wrote the manuscript.

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