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Review

The impact of receiving a diagnosis of Non-Epileptic Attack Disorder (NEAD): A systematic review

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ABSTRACT

Background: Clinicians have reported observations of the immediate cessation of non-epileptic attacks after the diagnosis of NEAD is presented.
Objective: The purpose of this systematic review was to examine the impact of receiving a diagnosis of NEAD.
Search strategy: A literature search across the databases Medline, PsycINFO, EMBASE, and CINAHL, and additional hand searching, identified six original studies meeting criteria for the review.
Selection criteria: Included studies were original peer-reviewed articles investigating the impact of receiving a diagnosis of NEAD on adult populations with at least one outcome measured pre- and post-diagnosis.
Analysis: The studies were assessed for methodological quality, including biases. This assessment was developed to include criteria specific to research regarding NEAD and diagnosis.
Results: Six identified studies, with a total of 153 NEAD participants, examined the impact of receiving a diagnosis on seizure frequency. Two of the six also examined the impact on health-related quality of life. The findings were inconsistent, with approximately half the participants experiencing seizure reduction or cessation post-diagnosis. Diagnosis appeared to have no significant impact on health-related quality of life. The overall evidence lacked quality, particularly in study design and statistical rigour.
Conclusions: Mixed results and a lack of high quality evidence were found. Concerns are considered regarding the appropriateness of seizure frequency as the primary outcome measure and the use of epilepsy control groups. Indications for future research include: measuring more meaningful outcomes, using larger samples and power calculations, and ensuring consistent and standard methods for communicating the diagnosis and recording outcomes.

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Introduction

Non-Epileptic Attack Disorder (NEAD) is the diagnostic term for people who experience non-epileptic attacks [1], also commonly referred to as Psychogenic Non-Epileptic Seizures (PNES). Although many terms have been used historically [2], in this review the terms non-epileptic attacks and NEAD will be adopted. Non-epileptic attacks have been defined as: episodes of altered behaviour which resemble epileptic seizures but are absent of the characteristic clinical and electrographic features of epilepsy [3].

Whilst epilepsy is caused by excessive discharges in the brain, non-epileptic attacks (when other physiological causes are ruled out) are considered to have psychological causes [4]. Although there is no universally accepted theory [5], attacks are widely thought to occur in response to overwhelming distress triggered by difficult situations, thoughts, and emotions [6]. With NEAD patients mainly entering neurology services, the involvement of psychology has been delayed. With growing clinical and academic interests [7], it is anticipated that theoretical understanding and clinical implications will develop.

It has been estimated that 20%–30% of patients in neurology clinics for suspected epilepsy actually have NEAD [8,9]. Due to the topographical similarities, NEAD is often misdiagnosed as epilepsy, leading to inappropriate and potentially damaging treatment with antiepileptic drugs [10]. It takes an average of seven years before a revised NEAD diagnosis is reached [11]. To remedy this much of the research effort has focused on developing and validating a robust method for the differential diagnosis of NEAD [12]. The method of diagnosis considered as the gold standard for sensitivity and specificity involves video-electroencephalogram (V-EEG) monitoring, whereby the

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electroencephalogram (EEG) records brainwave activity which is considered in conjunction with the clinical characteristics of the seizures observable on the video [13,14]. However, to complicate diagnosis and appropriate treatment, research using V-EEG data suggests that NEAD is co-morbid in up to 10% of epilepsy patients [15,16]. Research into treatment for NEAD has only recently received the attention of systematic reviewers, concluding that high quality evidence for effective treatments is lacking [17,18].

With comprehensive psychological theories and treatments yet to be established, clinicians often lack a good understanding of NEAD [19]. Consequent inadequate (potentially stigmatising) explanations to the patient can lead to confusion, anger, and disagreement with the diagnosis. Such reactions were associated with a poorer prognosis in terms of attack frequency and severity, and quality of life [19]. To provide clinicians with an adequate and non-stigmatising explanation for patients, several protocols have been developed [20–22].

Rationale

Within the literature, receiving a NEAD diagnosis is often referred to as the first stage of treatment [23–25]. This appears based on observations by clinicians that diagnosis can be interventive. Over the years clinicians have observed the communication of the diagnosis to result in the immediate cessation of attacks in some patients, negating the need for further treatment [e.g. 10,26]. To the author's knowledge research has not attempted to explain this phenomenon, or the difference between those whose attacks cease and those whose attacks continue. As with many aspects of NEAD, theory development has fallen short, with categorisation taking its place [27–29].

Being aware of the reports that receiving a diagnosis can reduce/eliminate seizures, neurologists may be more considerate with their communication of the diagnosis, seeing it as a possibly effective therapeutic task. On the other hand, it may perpetuate the historic perception of non-epileptic attacks being considered factitious/malingering [30]. As the role of neurology post-diagnosis is yet to be widely agreed and implemented [31], these reports may serve to support services' decisions to discharge patients from neurology upon diagnosis and offer no follow-up or formal pathway into psychology services. This lack of agreement on the role of neurology post-diagnosis is one factor contributing to the slow progress in establishing standard and effective management for patients [32].

With the reports of diagnosis having a positive impact being well known and perhaps influential, it is important to consider the evidence as a whole before any conclusion should be made.

Aims

This review aims to synthesise the evidence regarding the impact of receiving a diagnosis of NEAD. The purpose of this review is to ascertain what the diagnosis impacts on, and whether the evidence is sufficient to draw any specific conclusion regarding the therapeutic effect of diagnosis.

Method

Searching

As previously noted the variation in terminology used in place of non-epileptic attacks and NEAD necessitated a comprehensive and inclusive search approach. Also, due to the paucity of literature in this area, historically used terms now deemed pejorative, such as hysterical seizures, and terms encompassing many phenotypes, such as somatoform disorders, were also included. For searching the databases, groups of terms relevant to two specific elements of the question were combined: non-epileptic attacks and NEAD; and diagnosis and outcome.

Electronic searches were as follows:

- CINAHL (1981 to July, week 3, 2014);
- EMBASE (1980 to 2014 Week 29);
- Medline (1947 to July week 3, 2014); and
- PsycINFO (1910 to July week 3, 2014).

The chosen databases include research literature from social science, nursing, and medical professions. Covering this range of disciplines was necessary due to the changing conceptualisation and continued variation in the management of NEAD patients. For full search strategies see supplementary information (online only). Additionally, the reference lists of included studies and several relevant reviews [5,38,39] were hand searched.

Selection

In order to meet the aims of the review, priori inclusion and exclusion criteria were developed.

Literature was included if it:

- was original research;
- included adult participants;
- explored the impact of receiving a diagnosis of NEAD (or one of its other known terms) with the requirement that seizures with psychogenic non-epileptic origin rather than other medical causes were identified;
- included one or more outcome measure with data recorded/collected pre- and post-diagnosis; and
- was written in English (due to the constraints of the study translation being not possible).

Literature was excluded if it:

- did not specify that the diagnosis was the only ‘intervention’ before outcome data was collected, or if active treatment/intervention was reported following the delivery of the diagnosis and before follow-up data was collected;
- was not published in a peer-reviewed journal; and
- was not an article length representation of the study (required to assess quality).

A total of 8011 articles were identified. The first author reviewed the titles and abstracts of articles for relevance. Articles were excluded at this stage for obvious violations of the inclusion criteria including: unrelated subject matter, papers other than original research and research with non-NEAD populations e.g. other somatoform disorder types. 196 papers remained after this process, and 144 after duplicates were removed.

Some articles remained due to the information in the abstract not allowing suitability to be determined, or because no abstract was immediately accessible. Four publications were found to be conference abstracts and were therefore excluded. The authors reviewed full texts for the remaining 140 articles to determine eligibility. Further papers were excluded for the obvious violations of inclusion criteria and other reasons including: active treatment before follow-up, presence of treatment not specified, retrospective data collection, and baseline data collected post-diagnosis.

Hand searching of the six included studies [26,33–37] and relevant reviews [5,38,39] identified 12 additional potential studies, with three remaining after the initial abstract sift. Of these, one was a conference abstract and two were excluded when the full-text was reviewed.

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