Doctorate in Clinical Psychology | Lancaster University

Psychological Inflexibility and Non-Epileptic Attack Disorder

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Word Count Statement

Section	Text	Appendixes, references and tables	Total
Thesis abstract	268		
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Abstract	190		
2. Empirical paper	9312	3859	13416
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Abstract

Overview: This thesis explored concepts important to the construct of psychological inflexibility within non-epileptic attack disorder (NEAD). NEAD is the presentation of seizure like attacks, which cannot be explained medically, and are thereby thought to be psychological in nature. Psychological inflexibility is defined as the view that one is unable to change their internal or external behaviour to be in accordance with their own desires and values. This exploration was done over the course of three separate papers: a systematic literature review, an empirical paper, and a critical appraisal of the thesis.

Systematic Literature Review: The systematic literature review explored avoidance within NEAD, through narrative synthesis and quantitative meta-analyses. The review identified that individuals with NEAD utilise avoidance more than individuals with epilepsy or healthy controls. Avoidance appears to be an important component of NEAD.

Empirical Paper: The empirical paper included 285 individuals with NEAD and utilised an on-line, one group observational design. Variables relevant to psychological inflexibility: cognitive fusion, experiential avoidance and mindfulness were explored in regards to relationships with three outcome variables in NEAD: somatisation, impact of NEAD upon life, and non-epileptic attack (NEA) frequency. It was found that all of the psychological inflexibility variables were correlated with somatisation and impact upon life. Only mindfulness was found to be correlated, with NEA frequency. Mindfulness was the only psychological variable which uniquely and independently predicted somatisation in NEAD. Somatisation in turn contributes significantly to the impact upon life and NEA frequency.

Critical Appraisal: Further background on the theory which was considered in the conceptualisation of this thesis are provided and future directions of research are discussed.

Declaration

This thesis was undertaken for the Doctorate in Clinical Psychology at Lancaster University, within the Division of Health Research. The work presented here is the author's own, except where due reference is made. The work has not been submitted for the award of a degree elsewhere. The author has no competing interests to report.

Name: Tasha Cullingham Signature: Date:

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Table of Contents

Word Count Statement....ii
Abstract....iii
Declaration....iv
Acknowledgements....v
Table of Contents....vi
1. Literature Review....1-1
Abstract....1-2
A Systematic Review of Avoidance in Non-Epileptic Attack Disorder....1-3
Avoidance as a Maintaining Factor....1-4
Method....1-7
Inclusion and Exclusion Criteria....1-8
Data Extraction....1-9
Meta-Analysis....1-9
Quality Assessment....1-9
Results....1-10
Quality Assessment....1-11
Study Characteristics....1-11
Sample Characteristics....1-12
Avoidance Measures....1-14
Key Findings....1-17
Meta-analyses....1-21
Discussion....1-22
References....1-29
Tables....1-38
Table 1....1-38
Table 2....1-39
Table 3....1-40
Figures....1-45
Figure 1 PRISMA Diagram....1-45
Figure 2 Forest Plot for HC compared to NEAD....1-46
Figure 3 Funnel Plot for HC compared to NEAD....1-47
Figure 4 Forest Plot for EC compared to NEAD....1-48
Figure 5 Funnel Plot for HC compared to NEAD....1-49

Appendix 1-A 1-50
Appendix 1-B 1-56
Appendix 1-C 1-57
2. Empirical 2-1
Abstract 2-2
Psychological Inflexibility, Somatisation and the Impact of Non-Epileptic Attack Disorder on a Person's Life 2-3
Non-Epileptic Attack Disorder 2-3
Psychological Support for Individuals Experiencing NEAD 2-6
Acceptance and Commitment Therapy 2-6
ACT and NEAD 2-9
Research Aims and Questions 2-11
Methods 2-13
Design 2-13
Participants 2-13
Analysis 2-14
Materials 2-15
Demographic information and diagnosis information. 2-17
Results 2-18
Somatising 2-19
Impact Upon Life 2-20
Experiential Avoidance 2-20
Cognitive Fusion 2-21
Mindfulness 2-21
NEA Frequency 2-21
Correlations 2-21
Research Question One: What are the Relationships between CF, EA, levels of Mindfulness, and Somatisation in NEAD? 2-22
Research Question Two: Do the Psychological Inflexibility Variables, NEA Frequency and Somatisation Predict Perceived Impact of Life within the NEAD Population? 2-23
Research Question Three: Do Mindfulness, EA, CF, and Somatisation Predict NEA Frequency? 2-24
Discussion 2-25
Research Question One: What are the Relationships between CF, EA, levels of Mindfulness, and Somatisation in NEAD? 2-26

Research Question Two: Do the Psychological Inflexibility Variables, NEA Frequency and Somatisation Predict Perceived Impact of Life within the NEAD Population? 2-28
Research Question Three: Do Mindfulness, EA, CF, and Somatisation Predict NEA Frequency? 2-29
Overall Findings 2-32
Limitations 2-33
Clinical Implications 2-35
Future Research 2-36
References 2-38
Tables 2-50
Table 1 2-50
Table 2 2-51
Table 3 2-52
Table 4 2-53
Table 5 2-54
Table 6 2-55
Figures 2-56
Figure 1. Proposed model for future research 2-56
Appendix 2-A 2-57
Tests of Normality 2-57
Appendix 2-B 2-58
Mann Whitney tests comparing NEAD with epilepsy to NEAD only 2-58
Appendix 2-C 2-59
Assumptions for linear regression with somatisation as the dependent 2-59
Appendix 2-D 2-61
Assumptions for linear regression with impact on life as the dependent 2-61
Appendix 2-E 2-63
Assumptions for ordinal regression with NEA frequency as dependent 2-63
Appendix 2-F 2-64
Author guidelines for target journal Seizure 2-64
3. Critical Appraisal 3-1
Critical Appraisal of the Thesis Psychological Inflexibility Within Non-Epileptic Attack Disorder 3-2
Outcome Variables Within NEAD 3-5

Findings of This Thesis 3-6
Measurement Difficulties 3-9
References 3-12
4. Ethical Proposal 4-1
Faculty of Health and Medicine Research Ethics Committee Form 4-2
Research Protocol 4-3
Participant Information Sheet 4-9
Consent Form 4-11
Eligibility 4-12
Debrief Sheet 4-13
Demographics Form 4-14
Work and Social Adjustment Scale 4-15
Acceptance and Action Questionnaire Two 4-16
Mindful Attention Awareness Scale 4-17
Difficulties in Emotional Regulation Scale 4-18
Cognitive Fusion Questionnaire 4-19
The Physical Health Questionnaire-15 4-20
Lancaster University Data Management 4-21
Advertising Material 4-23

1. Literature Review

A Systematic Review of Avoidance in Non-Epileptic Attack Disorder

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Lancaster University Doctorate in Clinical Psychology

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Abstract

Background: Avoidance is the active process of trying to not experience or escape from situations, places, thoughts or feelings. This can be done through behavioural or cognitive strategies, or more broadly, a combination of both, utilised in an attempt to disengage from private experiences referred to as experiential avoidance (EA). Avoidance is considered important in the development and maintenance of non-epileptic attack disorder (NEAD). However, research has yet to be systematically synthesised. This review aimed to explore avoidance within an adult NEAD population.

Methods: Fourteen articles were identified by searching CINAHL, MEDLINE Complete, PsycINFO, and EMBASE and were combined in a narrative synthesis. Six of these articles were included in a meta-analysis comparing levels of EA for individuals with NEAD and healthy controls (HC) and four were included in a meta-analysis comparing EA in NEAD to epilepsy controls (EC).

Conclusions: EA appears to be a strategy which is used in a high proportion of the NEAD population. The NEAD group utilised significantly more avoidance compared to both HC and EC. However, further research is needed to understand the extent and types of avoidance which are relevant to the NEAD population.

A Systematic Review of Avoidance in Non-Epileptic Attack Disorder

Non-epileptic attacks (NEAs) are involuntary episodes resembling epileptic seizures which are believed to be caused and maintained by psychological factors rather than biological physio-pathology (Binzer, Stone, & Sharpe, 2004; Bodde et al., 2009; Bodde et al., 2007; Brown et al., 2013; Brown & Reuber, 2016a). Non-epileptic attack disorder (NEAD) is a more common experience for women than men (Abubakr, Kablinger, & Caldito, 2003). The exact prevalence is unclear, with figures ranging from 2 to 33 individuals per 100,000 people (Brown & Reuber, 2016b; Francis & Baker, 1999; Goldstein et al., 2010), and NEAD accounting for between five and forty percent of diagnoses received by individuals referred to specialist epilepsy clinics (Robbins, Larimer, Bourgeois, & Lowenstein, 2016).

NEAD is a complex disorder and to date there is no clear singular psychological process which has been identified as critical to its development (Brown & Reuber, 2016a). Many psychological processes and environmental risk factors have been identified through meta-analysis such as somatisation, alexithymia, dissociation, childhood sexual abuse, insecure attachment, previous head trauma, and seizure exposure (Brown & Reuber, 2016a). Higher rates of childhood trauma (Alper, Devinsky, Perrine, Vazquez, & Luciano, 1993; Kaplan et al., 2013) and insecure attachment styles (Brown et al., 2013), have consistently been found within the NEAD population compared to epilepsy or general populations. Although both have been identified as risk factors, neither alone can explain the phenomenon of NEAD. Firstly, it is important to note that although childhood trauma is more commonly reported within the NEAD population, not all individuals with NEAD report these experiences (Fiszman, Alves-Leon, Nunes, Isabella, & Figueira, 2004) or have

insecure attachment styles (Brown et al., 2013). Secondly, psychological distress is a well-known sequela from difficult early childhood experiences. Childhood trauma has been implicated in experiencing voice hearing (Larkin & Read, 2008), inter-personal difficulties (Sabo, 1997), rumination (Heim, Newport, Mletzko, Miller, & Nemeroff, 2008), worry (Heim & Nemeroff, 2001), disassociation (Banyard, Williams, & Siegel, 2001), and somatisation (Brown, Schrag, & Trimble, 2005). Such research has been invaluable in understanding NEAD. However, it has generated limited guidance into areas for support and intervention for individuals experiencing NEAs.

Avoidance as a Maintaining Factor

Research is now needed on processes which may be triggered by such difficult experiences and contribute to the development and maintenance of NEAD and can, possibly, indicate potential therapeutic interventions. One factor which has been implicated as an important psychological process which may be related to experiencing medically unexplained symptoms following childhood abuse is experiential avoidance (EA). Kroska, Roche, and O'Hara (2018) found that the relationship between childhood distress and somatisation, which is the psychological process of physically expressing distress, was fully mediated by EA and levels of mindfulness. Within healthy college students EA was also found to mediate the link between childhood abuse and general psychological distress (Reddy, Pickett, & Orcutt, 2006). This suggests that although such events may be important in the formation of such difficulties, it is the resulting psychological processes, such as EA, which causes on-going distress. Therefore, NEAD is likely maintained by psychological processes that involve difficulty managing distressing feelings. In other words, unhelpful methods of coping with strong negative emotions may be a core component of NEAD.

Brown and Reuber's (2016b) theoretical integrative cognitive theory of NEAD suggests that stressors, such as childhood sexual abuse, insecure attachments, and previous head trauma, all contribute to the development of a 'seizure scaffold', a type of cognitive blueprint of a seizure. Once the 'seizure scaffold' is activated it is translated into a physical NEA due to a lack of inhibitory control (Brown & Reuber, 2016b). The triggering events of the 'seizure scaffold' are hypo/hyper arousal. It is at this point that coping strategies become particularly salient to the model, as this shift in emotional state may result from deleterious coping mechanisms, such as avoidance. Coping styles can either be behavioural or cognitive and can be conceptualised as either approach-based or avoidance-based with avoidance-based strategies negatively impacting psychological wellbeing (Lazarus & Folkman, 1991; Moos & Schaefer, 1993).

Avoidance is the active attempt to disengage or escape from thoughts, feelings, physical sensations, memories, experiences, or places (Ottenbreit & Dobson, 2004). A defining feature of avoidance is that it is an active process, whereas similar constructs such as dissociation are not believed to be active. Dissociation, although considered by some to be an extension of avoidant coping, is believed to be an automatic process which is beyond the awareness of the individual (Hetzel-Riggin & Wilber, 2010). The active process of avoidance can manifest as external behaviours which involve avoiding activities, places or things that trigger unwelcome thoughts and feelings, and/or avoidance can be internal, for example the use of cognitive and emotional strategies such as suppression and attentional distraction to prevent the experiencing of unwanted thoughts and feelings. EA refers to the broad definition of avoidance and encompasses both cognitive and behavioural strategies

which are used to avoid difficult private experiences as a result of a fear of such experiences (Hayes, Wilson, Gifford, Follette, & Strosahl, 1996).

The utilisation of EA as a coping mechanism is often perpetuated, as individuals hold meta-cognitions around the usefulness of this strategy, believing it to be helpful. The act of avoiding a situation, feeling, or thought, creates the illusion of not having to experience it (Hayes et al., 2004; Wells, 2002). These meta-cognitions are reinforced as EA has immediate gains, protecting individuals from experiencing unwanted pain and distress momentarily (Hayes et al., 2004). However, when utilised as a routine strategy, EA can instead have harmful consequences, increasing distress and reinforcing the perception that the way one responds to emotions is uncontrollable (Hayes et al., 2004; Mansell, Morrison, Reid, Lowens, & Tai, 2007; Wells, 2002). EA has been found within many conceptualisations of psychological distress, such as anxiety, depression, self-harm, post-traumatic stress, and somatising (Chawla & Ostafin, 2007). It is important to note that EA is not always a negative experience. As with the majority of psychological processes, it is only when EA is used in an excessive and overly rigid fashion, that it has negative impacts.

Within clinical practice, EA has been identified as a common feature of individuals with NEAD (Prigatano, Stonnington, & Fisher, 2002). Somatising, a core feature of NEAD, has been demonstrated to be positively correlated with avoidant coping strategies (Masuda, Mandavia, & Tully, 2014). Individuals with NEAD have been found to have more avoidant coping styles than healthy controls (Bakvis, Spinhoven, Zitman, & Roelofs, 2011). Furthermore, individuals with a diagnosis of NEAD demonstrate a reduced ability

to cope with stressful situations and are fearful of emotions (Myers, Fleming, Perrine, & Lancman, 2013).

Avoidance (inclusive of EA, behavioural, and cognitive) within NEAD has been explored within several empirical papers (Bakvis, Spinhoven, Zitman, & Roelofs, 2011; Francis & Baker, 1999; Goldstein & Mellers, 2006), and has been reviewed in a limited fashion under the broader constructs of emotional processing, coping styles, and defensiveness. However, published peer reviewed studies exploring the psychological mechanism of avoidance within NEAD have yet to be synthesised in a detailed and systematic way. This review aimed to explore avoidance (inclusive of behavioural, cognitive, and EA) within an adult NEAD population. A narrative synthesis of avoidance within the NEAD population as well as two meta-analyses of NEAD compared to control groups (healthy controls and individuals with epilepsy) were conducted.

Method

The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA; Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009) was used as a guideline. An a priori protocol was established and utilised to complete the review (see Appendix 1-A).

Search Strategy

To identify significant empirical papers, scoping searches were conducted using the Primo Central database and Google Scholar (Boland, Cherry, & Dickson 2014). Databases to be searched were identified via preliminary reading of key papers, as well as discussion with an academic librarian (Brown & Reuber, 2016a; Chawla & Ostafin, 2007). Cumulative Index to Nursing and Allied Health (CINAHL), MEDLINE Complete,

PsycINFO, and EMBASE were searched. All databases except for EMBASE were searched using the EBSCO host platform, OVID was used to search EMBASE. Searches were completed on November 10th 2017 and started from the inception date of each journal.

Search terms were comprised of free text and medical subject headings (MESH) where applicable, all terms were searched for in the title, abstract and keyword fields. NEAD and EA search terms were identified from previous literature and searched using the Boolean operator OR, the NEAD and EA search terms were then combined using the Boolean operator AND, see Table 1 for search terms. Following the identification of papers, hand searching was conducted on all identified papers as well as recently conducted systematic literature reviews, focusing on NEAD.

INSERT TABLE 1

Inclusion and Exclusion Criteria

Studies were included if NEAD and EA were explored in an adult population, using quantitative methodology. Studies were required to be peer reviewed and published in the English language or fully translated into English. Only studies which focused on the active process of avoidance were considered.

Studies which included young children <12 years or whose primary focus was on a child population (mean age <18 years), and/or people with intellectual disabilities, and studies combining patients with NEAD and/or other functional neurological disorders were excluded. Studies which did not focus on avoidance but considered related concepts such as dissociation and alexithymia were excluded as both processes are conceptualised as being unconscious and automatic (Hetzel-Riggin & Wilber, 2010).

Data Extraction

To create the data extraction tool, Brown and Reuber (2016a) was consulted. A bespoke data extraction form was created and then piloted against three papers, as no problems were identified, it was then used for the remaining studies. See Appendix 1-B for data extraction form.

Meta-Analysis

Papers included within the narrative synthesis were further searched to determine the feasibility and appropriateness of meta-analysis. Firstly, the potential control groups of epilepsy comparisons (EC) and healthy controls (HC) were identified. Therefore, two meta-analyses were conducted. Studies included within the meta-analyses were required to report raw original data, inclusive of means and standard deviations (SD) comparing EA levels to either an HC or EC group. If these data were not accessible via the published paper, then authors were e-mailed and the data were requested. Studies whereby the means and SDs of the variables of interest were unable to be obtained were not included. Random effects models were used, to allow for potential heterogeneity between the effects explored (Higgins & Green, 2011). As per Littell, Corcoran, and Pillai (2008, p. 97), an a priori hierarchy was used to determine which measure of avoidance would be included when multiple measures of avoidance were taken within one study see protocol in Appendix 1-A.

Quality Assessment

The Effective Public Health Practice Project (EPHPP; Thomas, 2003) tool was used to assess study quality. Applicable to all study designs, the EPHPP (Thomas, 2003) is a reliable and suitable tool to assess non-randomised studies (Deeks et al., 2003). The EPHPP evaluates studies on eight facets: study design, selection bias, confounders,

blinding, data collection, withdrawals and drop-outs, and intervention integrity. However, as no studies were intervention based, the intervention integrity category, was excluded. Each category was given a rating of weak, moderate, or strong; which was then used to create the overall rating. Studies with no weak ratings received an overall rating of strong, studies with one weak rating were moderate, and studies with two or more ratings of weak were rated as weak. Despite the strength of this tool, it is acknowledged that the lack of consideration of power is a limitation to its robustness. Quality assessment was independently conducted by two reviewers. An inter-rater reliability of greater than 85% was required prior to discussion, to ensure that rating was conducted appropriately. Any discrepancies were then discussed, and a final rating was agreed upon. If a consensus could not be reached, a third reviewer would be asked to independently rate the paper; the majority rating would then be used. This did not occur, as all reviewers were in agreement following discussion.

Results

Electronic searches identified 582 citations with 102 duplications. One article was identified via hand searching (Urbanek, Harvey, McGowan, & Agrawal, 2014), and thus 481 titles and abstracts were read to identify relevant articles, 459 citations were excluded based on title and abstract. The remaining 22 articles were read in full to determine eligibility for inclusion. Eight articles were excluded: five did not consider constructs which could be considered avoidance (Bodde et al., 2007; Brown et al., 2013; Harden et al., 2009; Myers, Fleming, Lancman, Perrine, & Lancman, 2013; Uliaszek, Prensky, & Baslet, 2012), two used a mixed NEAD and functional neurological disorder group (Gulec et al., 2014; Morris et al., 2017) and one was excluded as only a summary was translated

into English (Uhlmann, 2004). Thus, 14 papers were included in the narrative review, six of these articles were included in the meta-analysis comparing NEAD to an HC group and four were included in the meta-analysis comparing NEAD to an EC group (Figure 1).

INSERT FIGURE 1

Quality Assessment

Study quality is outlined in Table 2. Five of the studies received an overall rating of strong (Baslet, Tolchin, & Dworetzky, 2017; Frances, Baker, & Appleton, 1999; Goldstein & Mellers, 2006; Myers, Trobliger, Bortnik, & Lancman, 2017; Novakova, Howlett, Baker, & Reuber, 2015); eight received an overall rating of moderate (Bagherzade, Mani, Firoozabadi, & Asadipooya, 2015; Bakvis et al., 2011; Cronje & Pretorius, 2013; Dimaro et al., 2014; Goldstein, Drew, Mellers, Mitchell-O'Malley, & Oakley, 2000; Gul & Ahmad, 2014; Testa, Krauss, Lesser, & Brandt, 2012; Urbanek et al., 2014); and one received an overall rating of weak (Myers, Matzner, et al., 2013).

INSERT TABLE 2

Study Characteristics

Included studies were published between 1999 and 2017. All but one (Myers, Fleming, Perrine, et al., 2013) used a quasi-experimental case-control design using either a comparison group and/or an HC or EC group. Myers, Fleming, Perrine, et al. (2013) used an observational cross-sectional design. Four studies compared individuals with NEAD to both an HC group and an EC group (Bagherzade et al., 2015; Dimaro et al., 2014; Frances et al., 1999; Testa et al., 2012). Six compared NEAD participants to an HC group only (Bakvis et al., 2011; Cronje & Pretorius, 2013; Goldstein, Drew, Mellers, Mitchell-O'Malley, et al., 2000; Gul & Ahmad, 2014; Novakova et al., 2015; Urbanek et al., 2014).

Novakova et al. (2015) used normative data from 224 healthy participants supplied by the creators of the emotional processing scale-25 (EPS-25; Baker et al., 2010) as their control. Goldstein and Mellers' (2006) compared NEAD to an EC group, Myers et al. (2017) compared females to males with a diagnosis of NEAD, and Baslet et al. (2017) compared individuals with NEAD who had altered responsiveness during an NEA to individuals who did not. Six of the included studies were conducted in the UK (Dimaro et al., 2014; Francis & Baker, 1999; Goldstein, Drew, Mellers, Mitchell-O'Malley, et al., 2000; Goldstein & Mellers, 2006; Novakova et al., 2015; Urbanek et al., 2014), four in the USA (Baslet et al., 2017; Myers, Fleming, Perrine, et al., 2013; Myers et al., 2017; Testa et al., 2012), Bagherzade et al. (2015) was conducted in Iran, Bakvis et al. (2011a) in the Netherlands and Cronje and Pretorius (2013), and Gul and Ahmad (2014) in Pakistan.

Sample Characteristics

In total, 1215 participants were included (620 NEAD, 468 HC, 127 EC). There was no significant difference in mean participant age between NEAD comparison or control groups, other than Urbanek et al. (2014) where NEAD participants were found to be significantly older than the control group (Urbanek et al., 2014). Cronje and Pretorius (2013) included NEAD participants as young as 14 years old, however the mean age of participants was 32.77 (SD=14.40) and was considered an adult sample. Mean age of HC participants ranged from 23.9 (SD=3.09) to 42.97 (SD=13.93), NEAD participants mean age ranged from 28.36 (SD=3.93) to 40.87 (SD=12.88). The comparison groups ranged from a mean age 34.35 (13.43) to 39.4 (SD=11.49).

Within all studies there were more women than men. Nine of the twelve studies which had comparison and/or control groups matched participants for gender. The gender

matched studies had a percentage of female participants which ranged from 66% (Bakvis et al., 2011) to 86% (Novakova et al., 2015). Urbanek et al. (2014) did not match for participant gender, however no significant difference was identified between the proportion of males and females in each group. Bagherzade et al. (2015) and Goldstein and Mellers (2006) both had more females in the NEAD group. Testa et al. (2012) had more female participants in their NEAD and healthy control group than the EC group. Gul and Ahmad (2014) was the only included study which had approximately equal numbers of male and female participants.

Nine studies confirmed NEAD diagnosis using EEG-telemetry, the gold standard (Bakvis et al., 2011; Cronje & Pretorius, 2013; Dimaro et al., 2014; Frances et al., 1999; Goldstein, Drew, Mellers, Mitchell-O'Malley, et al., 2000; Goldstein & Mellers, 2006; Gul & Ahmad, 2014; Myers et al., 2017; Testa et al., 2012; Urbanek et al., 2014). It is worth noting that although Goldstein and Mellers (2006) used EEG–telemetry for the majority (56%) of NEAD participants, they were not able to confirm diagnosis using this technique for all participants due to insufficient NEA frequency for EEG-telemetry, in which instance history and clinical opinion of two consultant neurologists/neuropsychiatrists were used. Bagherzade et al. (2015) stated that NEAD diagnosis was confirmed via a physician, however further details were not provided. The remaining studies either did not confirm the NEAD diagnosis or report enough information to determine if participants' NEAD diagnosis was confirmed (Baslet et al., 2017; Gul & Ahmad, 2014; Myers, Fleming, Perrine, et al., 2013; Novakova et al., 2015).

Avoidance Measures

Thirteen studies measured avoidance using self-report measures (Bagherzade et al., 2015; Baslet, 2011; Cronje & Pretorius, 2013; Dimaro et al., 2014; Frances et al., 1999; Goldstein, Drew, Mellers, Mitchell-O'Malley, et al., 2000; Goldstein & Mellers, 2006; Gul & Ahmad, 2014; Myers, Fleming, Perrine, et al., 2013; Myers et al., 2017; Novakova et al., 2015; Testa et al., 2012; Urbanek et al., 2014). The reviewer identified all measures to be reliable and valid, as all had available psychometric data.

Ways of Coping Questionnaire (WCQ; Folkman & Lazarus, 1988). The WCQ was the most frequently used measure and was used by four studies (Bagherzade et al., 2015; Cronje & Pretorius, 2013; Frances et al., 1999; Goldstein, Drew, Mellers, Mitchell-O'Malley, et al., 2000). The WCQ (Folkman & Lazarus, 1988) is the most widely cited measure used to investigate coping styles (Lundqvist & Ahlström, 2006; Parker, Endler, & Bagby, 1993). Two subscales were considered relevant to avoidance: distancing and escape-avoidance. Distancing measures the amount that an individual tries to cognitively detach themselves from an event, and reduce the perceived significance. Escape-avoidance focuses primarily on behavioural avoidance (including substance use) as a coping mechanism. It also includes items pertaining to wishful-thinking, a form of cognitive avoidance (Folkman & Lazarus, 1988). Both subscales are believed to measure EA. However, distancing focuses more on a specific cognitive technique which involves trying to detach oneself from the experience (Hayes et al., 2004). The escape-avoidance subscale was thought to be a better measurement of the construct of EA than the distancing subscale, as escape-avoidance measures multiple elements of avoidance, and is more highly

correlated with a measure of EA (Bond et al., 2011). Both were considered within the narrative review; escape-avoidance was used in meta-analyses.

Coping Inventory for Stressful Situations (CISS; Endler & Parker, 1990). The CISS was used by two studies (Myers, Fleming, Perrine, et al., 2013; Myers et al., 2017). Avoidant oriented coping is measured by two subscales, distraction and social diversion, which both tap into the broad construct of EA, inclusive of both behavioural and cognitive avoidance (Endler & Parker, 1990).

COPE inventory (Carver, Scheier, & Weintraub, 1989). Only Testa et al. (2012) used the COPE, which measures coping style across 15 dimensions. There are four dimensions which are relevant to the broader concept of avoidance: mental disengagement, denial, behavioural disengagement, and substance use. Mental disengagement focuses on strategies to distract oneself from thoughts and feelings using both cognitive and observable behavioural strategies. The denial subscale asks questions about pretending events or feelings are not happening, primarily using cognitive strategies. The behavioural disengagement subscale focuses on giving up on events, relying on both cognitive and observable behavioural strategies of avoidance. Substance use focuses on behavioural avoidance using substances to avoid thoughts and feelings. All subscales except for substance use are thought to measure EA, whereas substance use is thought to only measure behavioural avoidance.

The Fear Questionnaire (Marks, 1979). Goldstein and Mellers (2006) used the Fear Questionnaire which is a reliable and valid measure of phobic behaviour whereby participants are asked how much they would avoid certain situations. There are three

subscales: agoraphobia, social phobia and blood and injury (Marks, 1979). The agoraphobia subscale was considered within the meta-analysis.

EPS-25 (Baker et al., 2010). Novakova et al. (2015) used the EPS- 25 (Baker et al., 2010), which has a five-factor structure, with avoidance and suppression subscales. Both subscales included behavioural and cognitive avoidance, and therefore were both considered to measure the construct of EA.

The Emotion Regulation Questionnaire (Gross & John, 2003). Gul and Ahmad (2014) used the emotion regulation questionnaire which identifies emotional regulation across two perspectives: cognitive reappraisal and emotional suppression. The emotional suppression subscale was considered to be a component of EA, as it measures the want to avoid emotions, both positive and negative, and has been correlated with higher levels of emotional distress, lessened experiences of positive emotions and heightened experiences of negative emotions (Gross & John, 2003).

The Courtauld Emotional Control Scale (CECS; Watson & Greer, 1983). Urbanek et al. (2014) used the CECS which is a 21-item scale evaluating emotional control and disengagement from emotions, both considered components of EA. The CECS asks participants to rate how often they employ specific response strategies to anxious, angry, and depressive feelings on a four-point Likert-scale. The scale provides a total score as well as subscales per emotion (angry, anxious, and depressive).

Multidimensional Experiential Avoidance Questionnaire (MEAQ; Gámez, Chmielewski, Kotov, Ruggero, & Watson, 2011). Dimaro et al. (2014) used the MEAQ which has a total score which measures behavioural and cognitive strategies of avoidance

as well as distress aversion and distress endurance. The total score was used in meta-anylses.

The Acceptance and Action Questionnaire-two (AAQ-II; Bond et al., 2011). The AAQ-II is a measure of EA and primarily focuses on cognitive strategies of avoidance and considers emotional aversion and fear of emotions. The AAQ-II was only used by Baslet et al. (2017).

Experimental Paradigm to Measure Avoidance. Only one study (Bakvis et al., 2011) used an experimental paradigm to measure avoidance. Bakvis et al. (2011) measured behavioural avoidance via trials which involved affect-approach incongruent and congruent conditions for happy and angry facial expressions. Within the congruent condition, participants were asked to approach happy faces and avoid angry faces; the opposite was required in the incongruent condition.

Key Findings

Of the ten studies which compared the levels of avoidance (EA and behavioural avoidance) of NEAD participants to HC, nine found avoidance to be significantly higher in the NEAD groups (Bagherzade et al., 2015; Bakvis et al., 2011; Cronje & Pretorius, 2013; Dimaro et al., 2014; Frances et al., 1999; Goldstein, Drew, Mellers, Mitchell-O'Malley, et al., 2000; Gul & Ahmad, 2014; Novakova et al., 2015; Urbanek et al., 2014). In the study by Bakvis et al. (2011) there was no difference between congruent and incongruent trials for the HC, whereas the incongruent condition took NEAD participants significantly longer ($p<.05$) to complete than the congruent task, demonstrating that individuals with NEAD have a higher propensity for socially avoidant behaviour. Only Testa, Krauss, Lesser, and Brandt (2012) found NEAD participants and HC to be statistically similar in their levels of

EA. It is worth noting that although the difference between groups was not found to be statistically significant, the NEAD group had higher mean T scores than the HC group across all subscales considered to tap into the construct of avoidance.

Four studies (Dimaro et al., 2014; Frances et al., 1999; Goldstein & Mellers, 2006; Testa et al., 2012) directly compared NEAD participants to an EC group. Dimaro et al. (2014) found that NEAD participants had significantly higher levels of EA than the EC group. Goldstein and Mellers (2006) found that individuals with NEAD used significantly more avoidance behaviours in relation to agoraphobia than individuals with epilepsy. However, no statistically significant difference was identified between the NEAD and EC group on avoidant behaviours relating to social phobia or blood and injury phobia. Although not statistically significant the means of both NEAD group were higher than the epilepsy group on both social and blood phobia. It is important to note based on post-hoc power calculations, conducted using G*power 3 (Faul, Erdfelder, Lang, & Buchner, 2007), Goldstein and Mellers (2006) would only have been able to detect a statistically significant difference for a large effect size $F(1,42)=.043$, considering 80% power, and an alpha value of .05. Frances et al. (1999) found no statistically significant difference between the levels of EA, as measured by the distancing and escape-avoidance subscale on the WCQ, used by the NEAD group and the EC group. Bagherzade et al. (2015) identified a difference between all groups using an omnibus analysis of variance (ANOVA), they did not specifically compare NEAD to EC groups in the pair-wise post-hoc tests. However, they provided the mean, SD, and sample size per group, therefore a t-test was conducted by the author. The NEAD group was found to use significantly more ($p<.001$) escape avoidance than the EC group. The NEAD group and the EC group were not found to differ

significantly on their levels of distancing (Folkman & Lazarus, 1988). This is again likely attributable to limited power as based on a post-hoc power analysis it was found that there was only a 27.5% chance of identfiying an effect. Testa et al. (2012), using analysis of covariance (ANCOVA) did not find a significant difference between the NEAD group and EC group on any measures of avoidance. However, it is possible that this finding may be attributable to limited power and the appropriateness of the statistical tests performed. Testa et al. (2012) did not have equal numbers of participants in each group, which detriments statistical power within ANCOVA (Hamilton, 1977). Furthermore, there is controversy surrounding the appropriateness of using ANCOVA within non-randomised designs (Miller & Chapman, 2001). Dimaro et al. (2014) using univariate binary logistic regression for group membership between NEAD and EC, found that EA made a unique contribution to identifying group membership (ß=.02, $p<.01$), with NEAD participants having higher levels of EA. Dimaro et al. (2014) also found that EA was correlated with 'seizure' frequency within the NEAD group ($r=.55$, $p<.05$) but not for the EC group ($r=-.02$, $p>.05$). Novakova et al. (2015), however, did not find a significant difference between EA levels based upon subgroupings of individuals with NEAD when group membership was based upon seizure frequency. In addition, Urbanek et al. (2014) stated that Spearman's correlations were run on self-reported NEA characteristics, including: how bothersome NEAs were found to be, severity, and frequency. However, no results were reported with regards to the correlations between avoidance and any seizure characteristic. Although not explicitly stated, this may indicate that no correlations were significant (positive correlations were reported with regards to additional measures taken such as alexithymia, and seizure severity).

Interestingly, Testa et al. (2012) considered bivariate correlations between participants' experiences of distress and coping style and identified that high levels of distress were positively correlated with higher scores on the denial subscale within the NEAD group ($r=.36$, $p<.001$). This relationship was only present in the NEAD group, and no significant relationship between coping styles and levels of distress were identified for the HC or EC groups. To further explore the understanding of the role that coping styles have in NEAD participants' distress, Testa et al. (2012) performed a median split, comparing coping styles of high distress NEAD participants to low distress NEAD participants. High distress NEAD participants experienced higher levels in two areas of avoidance: more mental disengagement ($p=.04$), and more denial ($p=.03$).

Different levels of avoidance were found based upon different sub-groupings of NEAD by the two studies which compared different groups of individuals with NEAD. Myers et al. (2017) who compared female with male NEAD patients found that males had higher levels of avoidance ($p=.001$). Baslet et al. (2017) found participants with diminished responsiveness during an NEA had significantly higher levels of avoidance ($p=.04$) than individuals who remained responsive during an NEA.

Finally, Myers, Fleming, Perrine, et al. (2013), the only study which did not use a comparison group, found that 15.9% of participants with NEAD endorsed high levels of avoidant coping (high levels identified as being 1.5 SDs above normative data) as measured on the CISS.

INSERT TABLE 3

Meta-Analyses

Two random effects meta-analyses were conducted using Review Manager version 5.3 (RevMan). The first focused on the standardised mean difference between HC and NEAD on levels of EA. The analysis included 207 individuals with NEAD and 208 HC, combining the data from six studies (Bagherzade et al., 2015; Cronje & Pretorius, 2013; Dimaro et al., 2014; Frances et al., 1999; Goldstein, Drew, Mellers, Mitchell-O'Malley, & Oakley, 2000; Gul & Ahmad, 2014). Novakova et al. (2015); Testa et al. (2012); and Urbanek et al. (2014) were excluded as the required data were not available. Bakvis, Spinhoven, Zitman, and Roelofs (2011) was not included due to heterogeneity concerns and the nature of the data. Although the funnel plot was not entirely symmetrical, publication bias was not observed due to the higher proportion of studies using smaller sample sizes being identified with lower standardised mean differences (Figure 2). No heterogeneity was identified, I^2=0%, and $\chi^2(5)$=3.95, p=.56. An overall large and significant effect was found d(95% CI) = 1.14 (.093,1.35), Z= 10.69, p<.00001. See Figure 3 for forest plot.

INSERT FIGURE 2 AND 3

The second meta-analysis included four studies (Bagherzade et al., 2015; Dimaro et al., 2014; Frances et al., 1999; Goldstein & Mellers, 2006). The analysis included 118 individuals with NEAD and 107 individuals with epilepsy. Potential risk of bias was identified by the funnel plot, although due to the small number of included studies it is possible that this difference is attributed to random error (see Figure 4). Due to the small number of studies included as well as the possibility of publication bias, the results of this meta-analysis should be considered with caution. Low levels of heterogeneity were

identified (I^2=14%, and χ^2 (3)= 3.5, p=.32). An overall large effect was found, with the 95% confidence interval placing the effect within the medium to large effect size categorisations d(95% CI) = .79 (.49, 1.08), Z= 5.22, p<.00001. See Figure 5 for forest plot.

INSERT FIGURES 4 AND 5

Discussion

The primary aim of this review was to provide a narrative synthesis of the empirical evidence which explores avoidance (inclusive of EA, behavioural avoidance, and cognitive avoidance) within an adult NEAD population. A secondary aim of this review was to quantify avoidance within the NEAD population and compare the levels of avoidance utilised by the NEAD population to control groups. Two control groups were identified, HC and EC. Therefore, two random effects meta-analyses were conducted; the first explored the amount of avoidance within the NEAD population when compared to HC and the second compared individuals with NEAD to an EC group. Large effect sizes were found for both meta-analyses indicating that NEAD groups reported higher levels of avoidance than HC and EC groups.

However, exploring the narrative results there are elements of the data which should be further discussed. Testa et al. (2012), which was excluded from both meta-analyses as the required data were not available, was the only study which did not report a significant difference between HC and NEAD groups. It is important to consider possible reasons for this finding. Although, the overall quality of the Testa et al. (2012) study was considered moderate, the EPHPP (Thomas, 2003) does not consider power, or the appropriateness of the statistics used, within its overall quality assessment rating. To

account for group differences Testa et al. (2012) used ANCOVAs with: gender, IQ, and education as covariates. Although a technique that is commonly used, there is controversy around the appropriateness of using covariates to adjust for group differences (Miller & Chapman, 2001). In simplified terms, ANCOVA 'controls' for differences by creating new adjusted means which would be the means if all levels of the covariates were held constant, then compares the new adjusted means. When used in a randomised design this can be highly effective to remove a confounding variable, reducing the error term and thus increase statistical power. However, this is problematic when used within non-randomised designs for two reasons. First, when used in a non-experimental design this can create an unrealistic comparison which is inherently flawed, as differences which are integral to the group may be controlled for. Second, within non-randomised designs, when the groups differ on the covariate it reduces the group effect, and instead of increasing power, decreases power and increases the chances of committing a type two error. Considering the limitation of the statistical analysis used, it is important to note that although the authors did not identify a significant difference, the NEAD groups did have higher means than the HC group across all subscales which measure avoidance. The use of avoidant style coping such as denial and mental disengagement were found to differentiate high distress from low distress NEAD participants, but not HC or EC groups (Testa et al., 2012).

The meta-analysis found the NEAD group utilised more EA than the EC group. The narrative results are predominantly consistent with this finding. For the meta-analysis only one scale per study was included as recommend by Littell et al. (2008) to ensure that the assumption of independence was not violated. It is important to discuss the findings of the papers and scales not included within the meta-analysis. Three of the five studies

identified that the NEAD group utilised at least one component of avoidance significantly more than the EC group (Bagherzade et al., 2015; Dimaro et al., 2014; Goldstein & Mellers, 2006). Goldstein and Mellers (2006) only found agoraphobic avoidance behaviours to be significantly higher in the NEAD group than the EC group. Goldstein and Mellers (2006) had limited power and therefore it is important to note that although not significantly different, the NEAD group had higher means in both blood and injury and socially avoidant behaviours than the EC group. Bagherzade et al. (2015) did not conduct direct comparisons between the NEAD group and the EC group. A t-test preformed using the data identified that the NEAD group was significantly higher on the escape-avoidance subscale. However, no significant difference was found between the NEAD and EC groups on the distancing subscale. Again, this is possibly attributable to power as the post-hoc analysis was under powered. Frances et al. (1999) did not identify a significant difference between EC and NEAD groups on the escape avoidance subscale of the WCQ (Folkman & Lazarus, 1988). The difference in the findings of these two studies may be attributed to how data were reported. Frances et al. (1999) used raw scores on the WCQ, whereas Bagherzade et al. (2015) used relative scores. Relative scores provide a weighted score based upon how much a person utilised one coping strategy compared to others measured on the WCQ. Raw scores do not consider the individual's reliance on a specific strategy. Vitaliano, Maiuro, Russo, and Becker (1987) recommend using the relative scores over the raw scores and all other included studies (Bagherzade et al., 2015; Cronje & Pretorius, 2013; Goldstein, Drew, Mellers, Mitchell-O'Malley, et al., 2000) which used the WCQ reported the relative scores. Testa et al. (2012) did not identify any significant difference on EA between the NEAD group and the EC group. Again, this finding is possibly

attributable to the methodological issues discussed above. It again seems likely that when compared to an epilepsy group, individuals with NEAD employ heightened levels of EA strategies.

EA, as a construct, contains both behavioural and cognitive strategies of avoidance and is a psychological process utilised with the NEAD population. However, questions arise as to the conceptualisation and measurement of EA and both behavioural and cognitive avoidance. Behavioural avoidance is the act of disengaging or avoiding a person, place, or thing to attempt to limit the distress that such situations are perceived to cause. Cognitive avoidance focuses on the cognitive strategies which individuals engage in to try and evade distressing thoughts, feelings, and sensations such as trying to switch their attention or suppress experiences which are distressing (Hayes et al., 2004). EA is thought to be the overarching strategy of not wanting to remain in contact with experiences which are perceived as distressing. Most of the included measures were believed to measure EA as they considered both cognitive and behavioural components of avoidance. One exception was the Fear Questionnaire which exclusively looked at behavioural avoidance and examined behavioural avoidance in relationship to specific fears. Therefore, given the measures used in the reviewed studies, it is not possible to consider the different components of avoidance within the NEAD population in a reliable and useful manner.

Clinicians often identify individuals with NEAD as being a highly avoidant (Robbins et al., 2016), and this is often a concept which is considered within the formulation and interventions offered to individuals with NEAD (Mellers, 2005). Although it seems likely that high levels of EA and behavioural avoidance are utilised within NEAD, it is unclear if this differs from other populations of individuals

experiencing psychological distress. EA has been identified as being a component of psychological distress across diagnosis, and trauma histories (Chawla & Ostafin, 2007; Hayes et al., 2004). Within the studies explored it is impossible to say if the high levels of EA observed within the NEAD population are related to NEAs or if they are more indicative of general psychological distress. There were no studies identified which compared EA in NEAD to clinical groups other than epilepsy. To further understand the role of EA within the NEAD population it is important that future studies explore the relationships between EA and NEAD compared to a clinical population experiencing emotional distress. Comparisons groups comprised of people who have been given a diagnosis of anxiety, depression or personality disorders may help to further understand this relationship. It is important to consider that only (Bakvis et al., 2011) controlled for anxiety levels. Even when controlling for anxiety levels, NEAD participants still displayed higher levels of avoidance behaviour compared to HC, indicating that avoidance, regardless of additional expression of psychological distress, such as anxiety, is likely an important component of NEAD.

Limitations

A key limitation of this study is the reliance on published data. Significant findings are more likely to be published than null findings. This limitation needs to be considered with regards to the effect sizes identified by the meta-analyses. It is possible that the found effect sizes are over estimations due to publication bias. In addition, the meta-analytic data was based upon a small number of studies and therefore the results should be interpreted with caution. The inclusion of published studies was utilised to ensure quality.

Most of the included papers used reliable and valid self-report measures. However, there are still limitations with the use of self-report data. Self-report data require a level of insight and emotional awareness. Individuals with NEAD have high levels of alexithymia and often struggle to identify internal thoughts and feelings (Myers, Fleming, Perrine, et al., 2013). Therefore, more research which uses experimental or observational paradigms and clinician reports in addition to self-report measures of avoidance would be beneficial. In addition, many of the participants in the study were female. Although this is ecologically valid, as there is a higher proportion of individuals with a diagnosis of NEAD than men (Abubakr, Kablinger, & Caldito, 2003), this is still considered a limitation of the data included within this review. This becomes particularly clear when considering the results of Myers et al. (2017) who identified that men and women have different levels of avoidance and possibly utilise avoidance in different ways.

Future Research

The findings of this review are consistent with previous studies which explored the NEAD population. Previous systematic reviews within NEAD have identified that methodological limitations and limited comparison groups make it hard to draw conclusions about the aetiology and roles that specific psychological mechanism may have in NEAD (Brown & Reuber, 2016a). Therefore, more research is needed to understand the role of avoidance (cognitive, behavioural, and EA) within the NEAD population. The extant literature does not provide insight into the way in which avoidance may contribute to the development and maintenance of NEAD. Two of the included studies (Baslet et al., 2017; Myers et al., 2017) found that avoidance was utilised to varying degrees within different NEAD sub-groups. This suggests that to understand the role(s) of avoidance,

close attention should be paid to the heterogeneous nature of NEAD (Baslet, Roiko, & Prensky, 2010).

EA may be a key therapeutic target in the treatment of NEAD. To further explore the role that avoidance has within the experience of NEAD it is recommended that treatment studies which specifically manage avoidance be conducted. Dimaro et al. (2014) recommend third wave cognitive behavioural therapies which target avoidance such as acceptance and commitment therapy (ACT) and dialectical behavioural therapy (DBT) may be beneficial for the NEAD population (Harris, 2009; Linehan et al., 1999). Furthermore, ACT has been demonstrated to be more effective than traditional cognitive behavioural therapies for individuals with high levels of avoidance (Davies, Niles, Pittig, Arch, & Craske, 2015). By focusing intervention studies on such therapies, researchers would be able to explore the impact that avoidance has in the support and recovery of individuals with NEAD. This review did highlight that avoidance is likely a difficulty which many people with NEAD experience. Reducing levels of avoidance has been linked with higher quality of life and reduced distress (Jones, Reuber, & Norman, 2016). Therefore, it appears relevant for clinical psychologists to consider avoidance and the impact this may have on people's lives when supporting individuals who struggle with NEAD.

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Tables

Table 1

Search terms for NEAD and Avoidance

NEAD terms combined with OR	Avoidance terms combined with OR
nonepileptic	experiential n1 avoidance
non epileptic	distract$
pseudoseizure$	suppress$
dissociative n3 seizure$	reappraisal
pseudoepilep$	cognitive n3 change
hysterical n3 seizure$	cognitive n3 appraisal
hysterical n3 convulsion$	coping n3 style
conversion n3 seizure$	coping n3 mechanism
psychogenic n3 seizure$	coping n3 strateg$
functional n3 seizure$	avoid$
functional n1 neurological	
conversion n1 disorder	

Note: Final searches combined NEAD and Avoidance terms with AND, n3 indicates that search terms must appear within three words of each other.

Table 2

Quality assessment table using the EPHPP tool (Thomas, 2003)

Study	Study Design			Selection Bias			Confounders			Blinding			Data Collection			Analysis	Overall
	Study Design	Randomised	Study design Rating	Representative	High % agreed	Selection of bias Rating	Groups the same	High % cofounders controlled	Confounders Rating	Assessor unaware	Participants unaware	Blinding Rating	Measures valid	Tools reliable	Data collection Rating	Statistics appropriate	
Bagherzade et al. (2015)	case control	no	M	likely	?	M	yes	<60%	S	?	?	M	yes	yes	S	yes	Moderate
Bakvis et al. (2011)	case control	no	M	**?**	**?**	W	no	>60%	M	?	?	M	yes	Yes	S	yes	Moderate
Baslet et al. (2017)	case control	no	M	likely	**?**	M	no	>60%	M	?	?	M	yes	Yes	S	yes	Strong
Cronje and Pretorius (2013)	case control	no	M	unlikely	**?**	W	yes	>60%	S	?	?	M	yes	yes	S	yes	Moderate
Dimaro et al. (2014)	case control	no	M	unlikely	**?**	W	yes	>60%	S	?	N	M	yes	no	M	yes	Moderate
Frances et al (1999)	case control	no	M	likely	**?**	M	yes	>60%	S	?	?	M	yes	yes	S	yes	Strong
Goldstein et al. (2000)	case control	no	M	unlikely	**?**	W	yes	>60%	S	?	?	M	yes	yes	S	yes	Moderate
Goldstein and Mellers (2006)	case control	no	M	likely	**?**	M	yes	>80%	S	?	?	M	yes	yes	S	yes	Strong
Gul and Ahmad (2014)	case control	no	M	unlikely	**?**	W	yes	>60%	M	?	?	M	yes	no	M	yes	Moderate
Myers et al. (2013)	cross-sectional	no	W	unlikely	**?**	W	-	-	-	?	?	M	yes	yes	S	yes	Weak
Myers et al. (2017)	case control	no	M	likely	**?**	M	yes	>60%	S	?	?	M	yes	yes	S	yes	Strong
Novakova et al. (2015)	case control	no	M	likely	yes	M	yes	>60%	M	?	?	M	yes	yes	S	yes	Strong
Testa et al. (2012)	case control	no	M	unlikely	**?**	W	no	>60%	M	?	?	M	yes	yes	S	no	Moderate
Urbanek et al. (2014)	case control	no	M	unlikely	No	W	no	>60%	M	?	?	M	yes	yes	S	yes	Moderate

Note: numbers relate to ratings provided by the *EPHPP tool (Thomas, 2003)*. Section ratings of S= strong, M = moderate, and W= weak.

Table 3

Results summary table showing: study characteristics, key findings, and measure of avoidance

Study	Location	Healthy Control Group	Comparison Group	NEAD Group	Avoidance Measure	Type of Avoidance	Key Findings
Bagherzade et al. (2015)	Iran	N=33 Mean Age=36.65 (SD not reported) 36% female 40% college educated	Temporal Lobe Epilepsy N =33 Mean Age = 35.67 (SD not reported) 27% female 60% college educated	NEAD diagnosed by physician N = 33 Mean Age = 39.9 (SD not reported) 66% female 13% college educated	WCQ Subscales used: distancing and escape-avoidance	Experiential	NEAD participants used significantly more escape avoidance ($p<.001$), and distancing ($p<.05$) than healthy controls. Although the means for NEAD participants were higher than the mean for the EC group, no post-hoc between group significant testing was conducted between the two groups. Using the mean, n, and SDs provided t-tests were conducted, identifying that the NEAD participants used significantly more escape-avoidance ($p<.001$) but not significantly more distancing ($p>.05$) than the EC group.
Bakvis et al. (2011)	The Netherlands	N = 20 Mean Age = 31.9 (SD=12.7) 75% female Education not reported	No comparison group	NEAD confirmed by EEG telemetry N=12 Mean age= 36.8 (SD=12.9) 66% female Education not reported	Approach-avoidance task	Behavioural	NEAD group showed higher levels of approach avoidance for angry faces than controls even with anxiety controlled for.
Baslet et al. (2017)	USA	No healthy control	NEAD with altered responsiveness during an NEA N=24 Mean age=39.13 (SD=11.23) 89.40% female 13.75 Mean years in education	NEAD intact responsiveness during an NEA N=47 Mean age=38.15 (SD=14.26) 91.7% female 13.00 mean years in education	AAQ-II Full scale used	Experiential	NEAD participants with altered responsiveness during NEA had higher levels of EA. Altered responsiveness during an NEA, was considered a more severe NEA.

Table 3

Results summary table showing: study characteristics, key findings, and measure of avoidance

Study	Location	Healthy Control Group	Comparison Group	NEAD Group	Avoidance Measure	Type of Avoidance	Key Findings
Cronje and Pretorius (2013)	South Africa	N=22 Age matched to NEAD group Gender marched to NEAD group 59% College educated	No comparison group	NEAD confirmed by EEG telemetry N=22 Mean age = 32.77 (SD= 14.4) 77% female 24% college educated	WCQ subscales used: distancing and escape avoidance	Experiential	NEAD group was higher on escape avoidance and distancing than HC. Post-hoc regression found that escape avoidance and distancing were significant negative predictors of health-related quality of life.
Dimaro et al. (2014)	UK	N=31 Mean Age=42.97 (SD=13.93) 67.7% female 25.8% university educated	Epilepsy N=25 Mean age=39.40 (SD=16.49) 64% female 28% university educated	NEAD confirmed by EEG telemetry N=30 Mean age=40.87 (SD=12.88) 73.3% female 16.3% university educated	MEAQ full scale used	Experiential	NEAD participants had significantly more EA than HC and EC group. EA and somatising could identify epilepsy or NEAD diagnosis in 83.6% of cases using logistical regression. EA was positively correlated with NEA frequency, and no correlation was found between seizure frequency and EA for the EC group.
Frances et al (1999)	UK	N=30 Mean Age=33.7 (SD=13.8) 66.6% female 12.2 mean years in fulltime education	Epilepsy N= 30 Mean age = 36.2 (SD=12.9) 66.6% female 14.5 mean years in fulltime education	NEAD confirmed by EEG telemetry N=30 Mean age = 36.9 (SD=13.7) 66.6% female 11.03 mean years in fulltime education	WCQ subscales used: distancing and escape avoidance	Experiential	Escape avoidance was higher for individuals with NEAD than HC group. There was no significant difference between the EC group and the NEAD group on either distancing or escape-avoidance. A significant difference was found using MANOVA between all three groups on the distancing subscale. However, results were not directly reported for the difference between HC and NEAD. Using the reported sample size, group means and SD, a t-test was conducted. The difference between HC and NEAD was found to be significant with p=.029.

Table 3

Results summary table showing: study characteristics, key findings, and measure of avoidance

Study	Location	Healthy Control Group	Comparison Group	NEAD Group	Avoidance Measure	Type of Avoidance	Key Findings
Goldstein et al. (2000)	UK	N=20 Mean age =35.95 (SD=8.46) 45% Female Education not reported	No comparison group	NEAD confirmed by EEG telemetry N=20 Mean age=34.35 (SD=13.49) 80% female Education not reported	WCQ subscales used: distancing and escape avoidance	Experiential	Escape-avoidance was significantly higher in the NEAD group than in the healthy control group. There was no significant difference found between HC and NEAD group on the distancing subscale.
Goldstein and Mellers (2006)	UK	No healthy control	Epilepsy N=19 Mean age= 35.84 (SD=10.81) 73.% females Education not reported	NEAD predominantly confirmed by EEG N=25 Mean age = 35.52 (SD=13.49) 76% female education not reported	Fear Questionnaire subscales: agoraphobia, social phobia, and blood and injury	Behavioural	The NEAD group was higher in agoraphobia subscale than the EC group however no differences were found for either social phobia or blood and injury subscales.
Gul and Ahmad (2014)	Pakistan	N=72 Mean age=23.93 (SD=3.09) 55.5% female 65.2% had further education beyond high school	No comparison group	NEAD diagnosis not confirmed N=72 Mean age=28.36 (SD=3.93) 51.8% female 58.3 had further education beyond high school	Emotion Regulation Questionnaire Emotional suppressions subscale	Experiential	The NEAD group had significantly higher levels of emotional suppression than healthy controls. Emotional suppression was linked with a deficit in cognitive switching and errors in a facial recognition task.

Table 3

Results summary table showing: study characteristics, key findings, and measure of avoidance

Study	Location	Healthy Control Group	Comparison Group	NEAD Group	Avoidance Measure	Type of Avoidance	Key Findings
Myers et al. (2013)	USA	No healthy control	No comparison group	NEAD diagnosis not confirmed N=82 Mean age =39.7 87.8% female Education not reported	CISS Avoidance subscales	Experiential	15.9% of patients endorsed heightened levels of EA, which was fewer than reported lower task oriented and elevated emotion coping EA was found to predict low positive emotions and was not predicted by demographic variables or trauma history.
Myers et al. (2017)	USA	No healthy control	Males with NEAD Mean age = 34.34 (SD=13.43) Education not reported	NEAD confirmed by EEG telemetry Females with NEAD Mean age = 37 (SD=13.29) Education not reported	CISS Avoidance subscales	Experiential	Women and men varied on EA, with men using more EA and had higher levels of depression. Women experienced higher levels of dissociation and were more likely to have experienced sexual abuse.
Novakova et al. (2015)	UK	EPS-25 data N=224 Median age=32 (SD not reported) 86.2 % female Education not reported	No comparison group	NEAD diagnosis confirmation not reported N=50 Median age=39 (SD not reported) 86.0% female Education not reported	EPS-25 Avoidance and suppression subscales	Experiential	Avoidance and suppression subscales of the EPS-25 were higher in NEAD then in the normative healthy control data. Of the five emotional process scores measured using the EPS-25 suppression was highest in the NEAD group. A trend which was not endorsed within the healthy control data. There was no difference in levels of avoidance or suppression when within NEAD group comparisons were done based upon seizure frequency.

Table 3

Results summary table showing: study characteristics, key findings, and measure of avoidance

Study	Location	Healthy Control Group	Comparison Group	NEAD Group	Avoidance Measure	Type of Avoidance	Key Findings
Testa et al. (2012)	USA	N=40 Mean age=39.65 (SD=11.32) 82.5% female Average highest grade of education 15.31	Epilepsy N=20 Mean age=36.6 (SD=12.52) Average highest grade of education 15.4	NEAD confirmed by EEG telemetry N=40 Mean age=36.67 (SD=11.17) 92.5% female Average highest grade of education 13.7	COPE mental disengagement, denial, behavioural disengagement, and substance use, subscales	Experiential, except for substance use subscale which is behavioural.	The NEAD group did not engage in significantly more mental disengagement, behavioural disengagement, substance abuse or denial than either the HC group or the EC group. There was a positive correlation between distress and use of denial as a coping strategy for the NEAD group, that was not found for either the HC control group or EC group.
Urbanek et al. (2014)	UK	N=88 Mean Age =27.2 (SD=9.3) 64% female 58.0% university educated	No comparison group	NEAD confirmed by EEG telemetry N=56 Mean age=39.2 (SD=13.6) 70% female 17.9% university educated	CECS Subscales of emotional control for angry, anxious, depressive and a total scale.	Experiential	The total scale on the CECS was higher in NEAD than in HC. Considering the individual subscales levels of controlling and avoiding emotions, the anxiety and depression subscales were higher in individuals with NEAD than HC. however, levels were not significantly different for anger subscales between HC and NEAD groups.

Figures

Figure 1 PRISMA Diagram

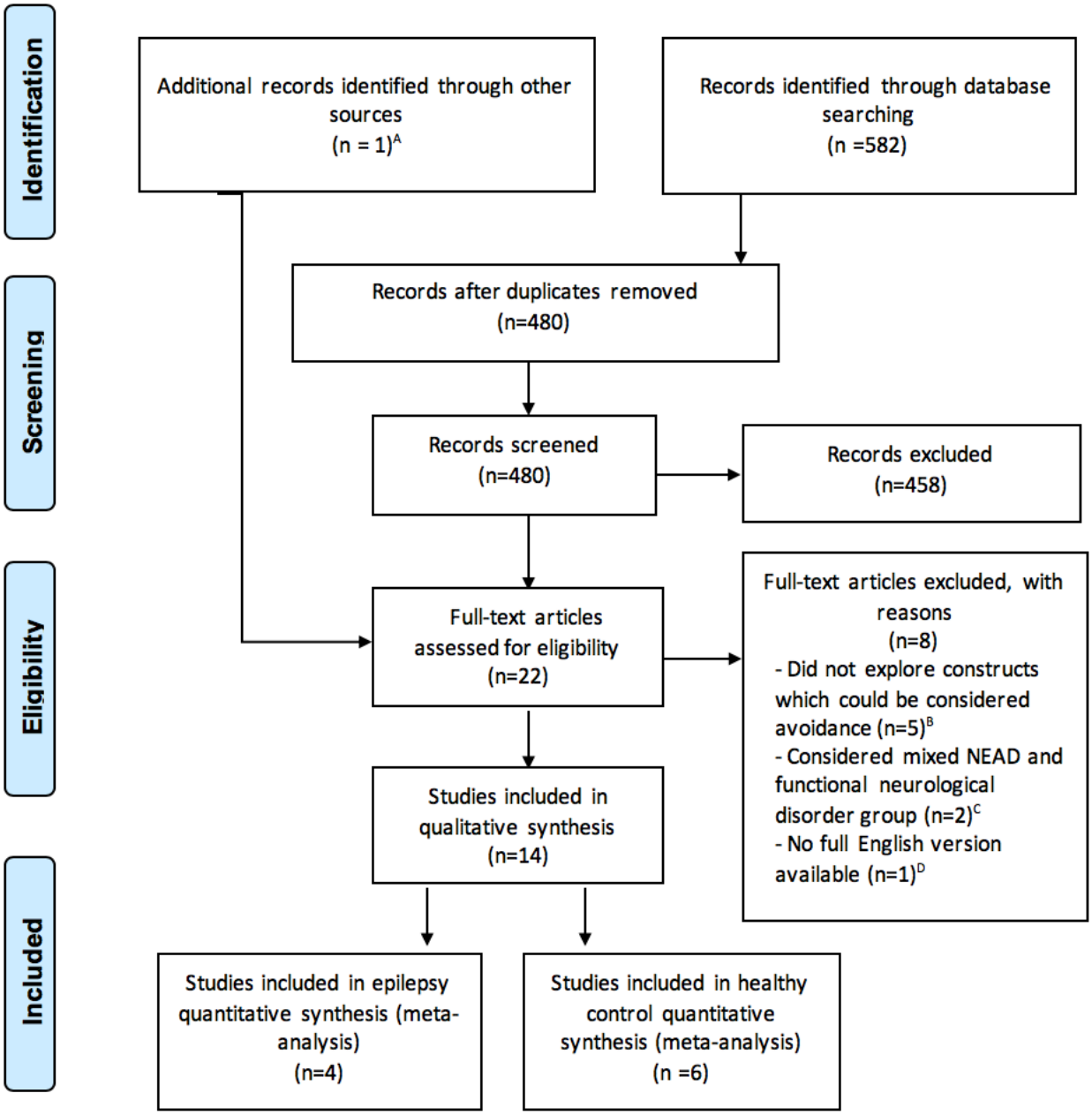


Figure 1 Prisma diagram for. Note. A = Urbanek et al. (2014); B = Bodde et al. (2007); Brown et al. (2013); Harden et al. (2009); Myers et al. (2013); Uliaszek et a. (2012); C = Gulec et al. (2014); Morris et al. (2017); D= Uhlmann (2004).

Figure 2 Forest Plot for HC compared to NEAD

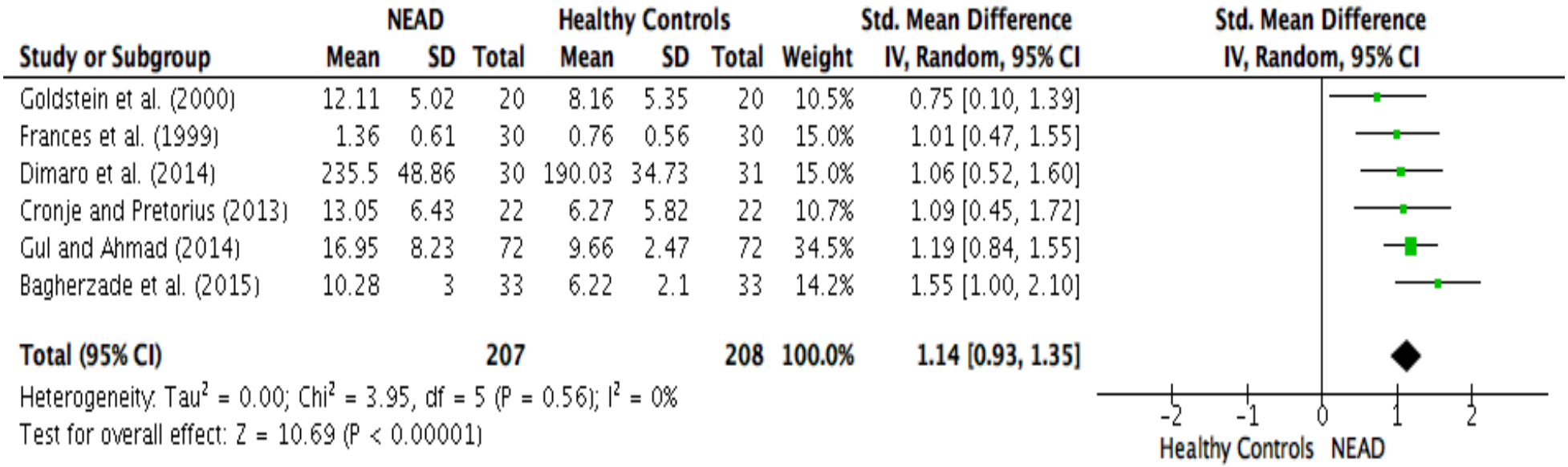
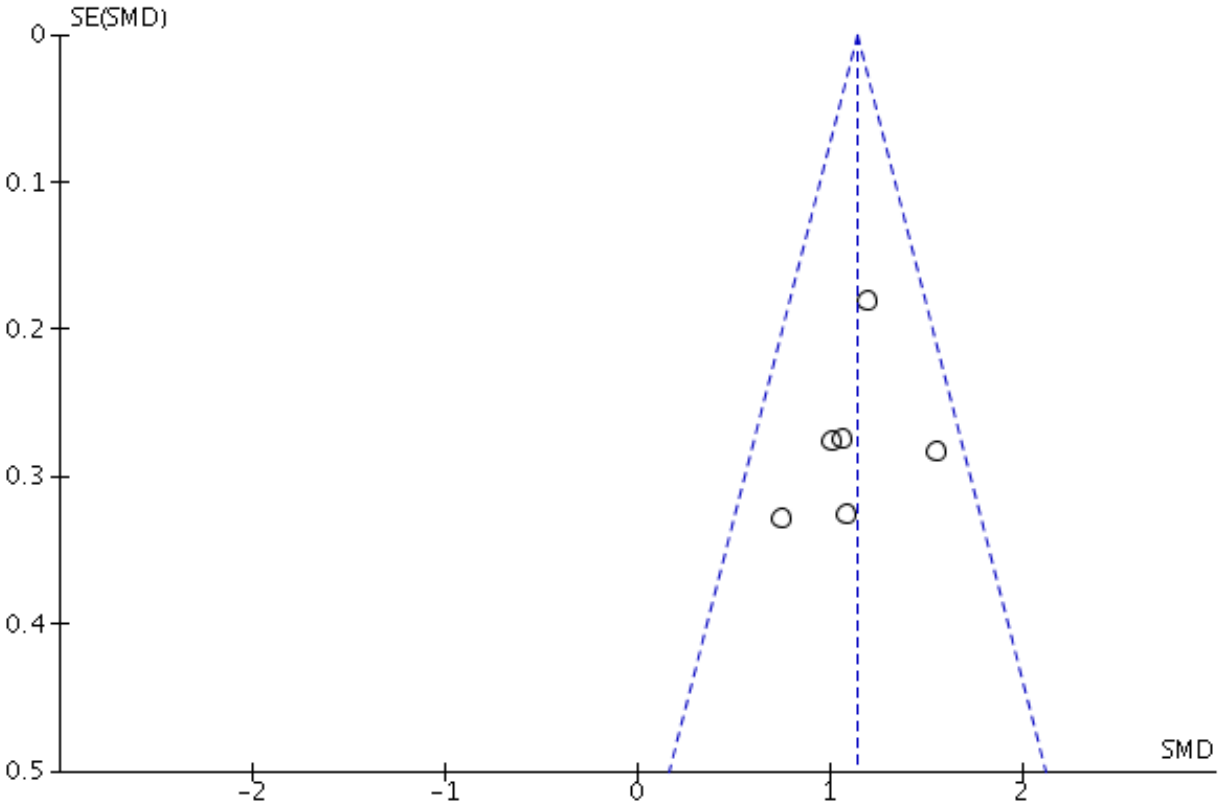


Figure 2 Forest plot for HC compared to NEAD groups on avoidance.

Figure 3 Funnel Plot for HC compared to NEAD



Figures 3. Funnel plot for NEAD compared to healthy control meta-analysis.

Figure 4 Forest Plot for EC compared to NEAD

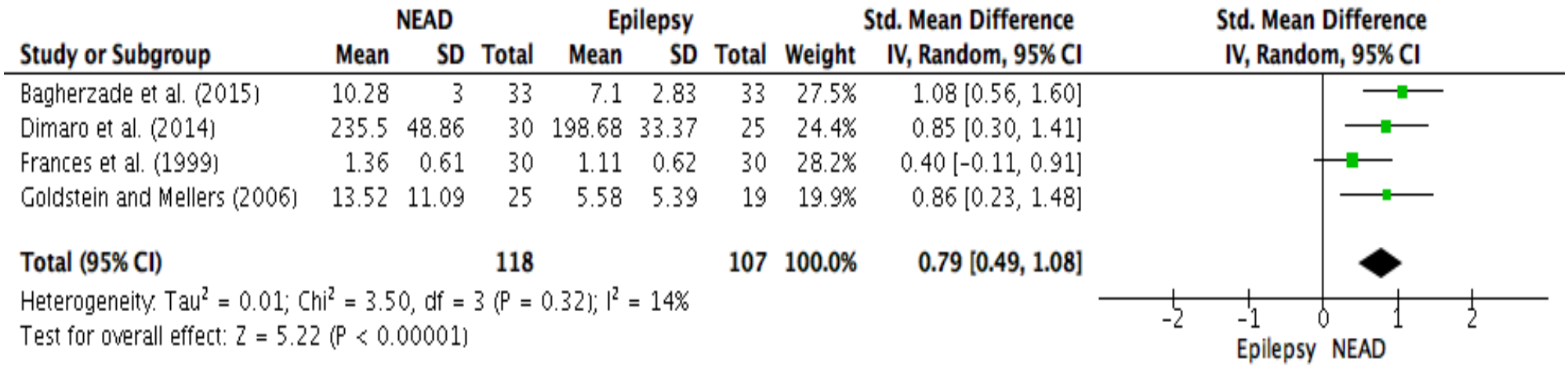


Figure 4. Forest plot for NEAD compared to EC group.

Figure 5 Funnel Plot for HC compared to NEAD

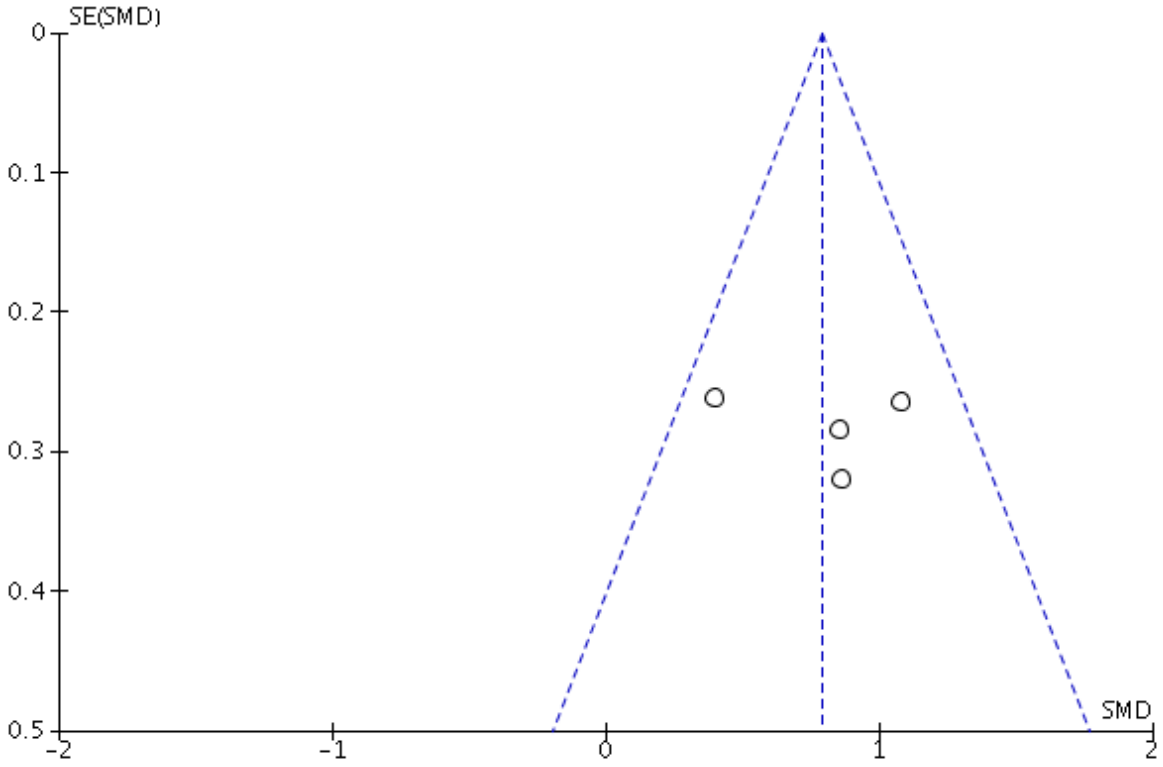


Figure 5. Funnel plot for NEAD compared to EC groups meta-analysis.

Appendix 1-A

Thesis SLR protocol

Non-epileptic Attack Disorder (NEAD) is the presence of paroxysmal movements, similar to epileptic seizures where no organic cause can be found (Brown & Reuber, 2016b; Francis & Baker, 1999) and instead the aetiology is believed to be rooted in psychological factors (Bodde et al., 2009). Literature has explored several mechanisms which may contribute to the development and maintenance of NEAD.

Brown and Reuber (2016a) conducted a large scale meta-analysis which explored several psychological components relevant to NEAD, including: dissociation, alexithymia, coping styles, trauma history, stressful life events, suggestibility, attentional dysfunction, relational difficulties, insecure attachment, anxiety, and somatisation. One mechanism which has been explored in NEAD which was only touched on briefly within Brown and Reuber (2016a) was avoidance. Avoidance was considered broadly within the constructs of emotional processing, coping styles and defensiveness, and was not considered as a mechanism in and of itself. Avoidance has been explored within the literature as a possible psychological mechanism which contributes to the maintenance of NEAD. The avoidance of thoughts and feelings can intensify and strengthen thoughts and emotions (Hayes, 2004). Therefore, in trying to avoid thoughts of a seizure, individuals may inadvertently be contributing to their seizure experiences and initiating the seizure scaffold as described by Brown and Reuber (2016b). In addition, avoidance has been discussed clinically as a common psychological feature of individuals experiencing NEAD (Prigatano, Stonnington, & Fisher, 2002). Despite this, there has not yet been a synthesis of the literature which explores the process of avoidance in NEAD.

Avoidance can present as behaviours which prevent the triggering of thoughts and feelings, or they can use cognitive and emotional strategies such as suppression and attentional distraction to prevent the experiencing of unwanted thoughts and feelings. Experiential avoidance (EA) is the repudiation of cognitive, emotional, or physical experiences. Although EA is believed to be an active process it can be either voluntary or involuntary and individuals are often not aware that they are engaging in experiential avoidance (Roberts & Reuber, 2014). EA has been linked with several psychopathologies: anxiety, depression, self-harm, post-traumatic stress, and somatising (Chawla & Ostafin, 2007). Dimaro et al. (2014) linked somatisation and experiential avoidance with individuals who had a diagnosis of NEAD. Individuals with NEAD often have more avoidant coping styles (Bakvis, Spinhoven, Zitman, & Roelofs, 2011) than healthy controls.

There is limited yet sufficient evidence to conduct a meta-analysis of EA in NEAD. However, based on the mixed methodology of identified and known papers, conducting a meta-analysis alone would challenge the utility of the review. Therefore, a narrative synthesis will be conducted on EA more broadly and a meta-analysis will be completed on papers which are homogenous enough, based on methodology and Cochrane's Q, and compare EA in NEAD to EA in healthy controls. This will identify the effect size of EA in NEAD compared to healthy controls and explore the literature which considers EA in NEAD more generally.

Search Strategy

Search Terms

NEAD terms Taken from Brown and Reuber (2016) (nonepileptic) OR (non epileptic) OR (pseudoseizure$) OR (dissociative n3 seizure$) OR (dissociative n3 convulsion$) OR (pseudoepilep$) OR (hysterical adj seizure$) OR (hysterical adj convulsion$) OR (hysteroepilepsy$) OR (conversion adj seizure$) OR (psychogenic adj seizure$) OR (functional adj seizure$) OR

Experiential Avoidance terms Taken from O'Driscoll, Laing, and Manson (2014)

(Experiential adj avoidance) OR Distract$ OR (attentional adj deployment) OR (*attention adj control)* Suppression OR Reappraisal OR (cognitive adj change) OR (Cognitive adj appraisal) OR Acceptance OR Resignation OR (coping adj style?) OR (coping adj mechanism?) OR (coping adj strateg$)

Experiential Avoidance Terms Taken from Chawala and Ostafin (2007)

Acceptance and Action Questionnaire; Avoidance

Databases

Medline Complete, EMBASE, PSYCinfo (Brown & Reuber, 2016; O'Driscoll, Laing, & Manson, 2014) , PSYarticles

Time Period

From journal inception date until final search date estimated to be conducted in January 2018.

Search Process Evaluation

The search results will be evaluated against a known subset of papers identified through previous systematic review Brown and Reuber (2016) and hand searching.

Selection Criteria

Inclusion Criteria

Must explore NEAD and avoidance in the adult population, using quantitative methodology. Studies must be peer reviewed studies published in English or translated into English to be included. As defined by Chawla and Ostafin (2007), avoidance will be considered both behavioural and emotional. For those to be included within the meta-analysis, studies must use a control group with healthy controls.

Exclusion Criteria

As per Brown and Reuber (2016a), studies which focus on children (<18 years) with a diagnosis of NEAD, on people with intellectual disabilities, and studies combining patients with NEAD and other functional neurological disorders (FND) will be excluded. Studies which focus on dissociation and alexithymia will be excluded as both processes are conceptualised as being unconscious versus conscious processes.

Studies which do not use a healthy control group will be excluded from the meta-analysis. Prior to the conduction of the meta-analysis, Cochrane's Q will be performed to determine if the papers are homogenous enough to be considered for a meta-analysis.

Quality Assessment

Deeks et al. (2003) conducted an SLR on non-randomised studies and identified six tools as suitable in the assessment of quality of non-randomised studies. The Effective Public Health Practice Project (EPHPP; Thomas, 2003) tool was selected and used to assess the quality of the included studies as this tool works with all study designs and was a reliable and suitable tool to assess non-randomised study quality. The quality assessment will be conducted by the lead investigator and a peer, agreement on quality will then be considered and disagreements discussed, if an agreement cannot be reached then the academic supervisor will be sought for support. Quality assessment

will be done digitally and once completed, the sheet will be printed and attached to each of the printed versions of the included articles.

Data Extraction

A bespoke data extraction form will be created and piloted against three papers. To create the data extraction tool, the Brown and Reuber (2016a) data extraction form will be consulted. Following this, the data extraction form will be reviewed with academic supervisors and changes will be made if needed. All changes will be recorded and a changes section will be added to this document if needed. Data extraction will be done digitally and saved in an Excel file. A copy of each individual sheet will then be attached to printed versions of all included articles.

Synthesis

The review will involve a narrative synthesis of all included papers, in addition a sub-set of papers which met the specified criteria, and if deemed to be homogeneous, based upon Cochrane's Q will be included within the meta-analyses. The meta-analysis will explore effect size of experiential avoidance when compared to a healthy control group. Due to the limited and varied literature, it is not appropriate to conduct a meta-analysis on all papers which met criteria for the systematic narrative review.

A Priori Selection of Measures

If a full scale of an avoidance measure was provided than that will be used. If there is no full scale available than subscales which consider the broadest definition of avoidance will be selected. Subscales which focus on both behavioural and cognitive elements of avoidance and if correlated to measures of EA these scales will be used. If a measure only focuses on behavioural or cognitive avoidance then the scale which is considered to generalise to the most situations will be used.

Schedule

Time line for project

Activity	Date	Responsibility
Review SLR protocol	November 2017	Supervisors
Conduct search	November 2017	Tasha
Write introduction	November 2017	Tasha
Write methods	December 2017	Tasha
Review data and conduct analysis	December 2017	Tasha
Write results and discussion	December 2017	Tasha
Proof read and complete tables	January 2018	Tasha
Draft one to be submitted	January 8th 2018	Tasha → Fiona
Draft two to be submitted	March 19th 2018	Tasha → Fiona

Refernces

Bakvis, P., Spinhoven, P., Zitman, F. G., & Roelofs, K. (2011). Automatic avoidance tendencies in patients with Psychogenic Non Epileptic Seizures. *Seizure, 20*(8), 628-634. doi:http://dx.doi.org/10.1016/j.seizure.2011.06.006

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Prigatano, G. P., Stonnington, C. M., & Fisher, R. S. (2002). Psychological factors in the genesis and management of nonepileptic seizures: clinical observations. *Epilepsy & Behavior, 3*(4), 343-349.

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Appendix 1-B

Data Extraction Form

Paper
Location
Design
Control group n=
Description
Age
% female
Education
Ethnicity
Employment
Social Economic Status
Comparison group n=
Description
Age
% female
Education
Ethnicity
Employment
Social Economic Status
NEAD group n=
Description
NEAD diagnosis confirmed by
Age
% female
Education
Ethnicity
Employment
Social Economic Status
Groups the same Y/N
Measure of Avoidance
Subscales
Types of avoidance
Statistics used
Description
Power
Effect size
Specified p value
Conclusions
Additional comments

Appendix 1-C

Author Guidelines for Seizure

SEIZURE - EUROPEAN JOURNAL OF EPILEPSY

AUTHOR INFORMATION PACK

TABLE OF CONTENTS

- **Description** p.1
- **Audience** p.1
- **Impact Factor** p.1
- **Abstracting and Indexing** p.2
- **Editorial Board** p.2
- **Guide for Authors** p.4

ISSN: 1059-1311

DESCRIPTION

Seizure - European Journal of Epilepsy is an international journal owned by Epilepsy Action (the largest member led epilepsy organisation in the UK). It provides a forum for papers on all topics related to **epilepsy** and **seizure disorders**.

Seizure focuses especially on **clinical** and **psychosocial** aspects, but will publish papers on the basic sciences related to the condition itself, the differential diagnosis, natural history and epidemiology of **seizures**, as well as the investigation and practical management of seizure disorders (including drug treatment, neurosurgery and non-medical or behavioural treatments).

The journal reflects the social and psychological burden and impact of the condition on people with epilepsy, their families and society at large, and the methods and ideas that may help to alleviate the disability and stigma, which the condition may cause. The journal aims to share and disseminate knowledge between all disciplines that work in the field of epilepsy.

AUDIENCE

Epileptologists, neurologists, epilepsy specialist nurses, clinical neurophysiologists, pharmacologists, psychiatrists.

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GUIDE FOR AUTHORS

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INTRODUCTION

Types of articles

Seizure - European Journal of Epilepsy publishes the following types of article:

1.1 Peer-reviewed articles

a. Full reviews.

Seizure welcomes comprehensive reviews on all subjects relating to epilepsy and other seizure disorders. Authors planning/proposing are invited to discuss their ideas with Editor-in-Chief prior to submission. Full reviews should be preceded by an abstract. Full reviews should not exceed 7,000 words, include no more than 6 figures or tables and 150 references.

b. Focused reviews.

Seizure is keen to publish focused reviews, especially on the latest developments in particular fields or on topics which are currently debated by clinicians and researchers. Authors are welcome to approach the Editor-in-Chief with their idea for a focused review prior to submission. Focused reviews should be preceded by an abstract. Focused reviews should be 1,500-2,500 words, and include no more than 3 figures or tables and 50 references.

c. Full-length original research articles.

The body of the text of these articles should be limited in length to 4,000 words, and there should be a maximum of 6 figures or tables. Additional figures, tables and other material (such as associated videos) can be submitted as online only Supporting Information (see section 'preparation of manuscripts' for further details). Full length research articles should be preceded by an abstract. The body of the text of the article should be clearly structured into 1) Introduction, 2) Methods 3) Results, 4) Discussion, 5) Conclusion and 6) References.

d. Short communications.

Comprise a number of different kinds of previously unpublished materials including short reports or small case series. Short communications should be preceded by an abstract. The body of the text is limited to 1,400 words. There are no more than 12 references, and 2 figures or tables (combined).

e. Case reports (Clinical Letters), see also ***Interactive Case Insights*** below

Seizure will also publish particularly instructive case reports in the format of Clinical Letters. Clinical Letters will not be preceded by an abstract. The word count is limited to 1,000 words. Clinical Letters can only include a maximum of 4 references and 2 figures or tables (combined), authors may include additional reading as supplementary material.

f. Letters to the Editor

Letters containing critical assessment of papers recently published in the *Seizure - European Journal of Epilepsy* will be considered for publication in the correspondence section. Letters should not exceed 1,000 words including references as necessary, one table or one figure. Letters should be typed in double spacing, should have a heading and no abbreviations. If related to a previously published article, the article should be identified by title, author(s), and volume/page numbers. All letters are subject to editorial review. At the Editor's discretion, a letter may be sent to authors of the original paper for comment, and both letter and reply may be published together.

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Other contributions than original research or review articles will be published at the discretion of the Editor-in-Chief, with only editorial review. Such material includes: obituaries, workshop reports and conference summaries, letters/commentary to the Editors (500 word limit, exceptionally including figures or tables), special (brief) reports from ILAE Commissions or other working groups, book reviews and announcements.

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The Editor-in-Chief invites ideas for supplements or special editions of Seizure including meeting abstracts. Such materials may be published, but only after prior arrangement with the Editor-in-Chief. Supplements will incur a charge. The page rate for proposed supplements can be negotiated with the Editor-in- Chief. Special editions are issues of Seizure wholly or partially dedicated to one particular topic. They may be edited or co-edited by internationally recognised experts in their field. Such experts do not need to be members of the Editorial Board of Seizure and are welcome to approach the Editor-in-Chief with their ideas. Special editions of Seizure would be expected to contain the same kind of manuscripts which are published in normal editions.

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To avoid unnecessary errors you are strongly advised to use the 'spell-check' and 'grammar-check' functions of your word processor.

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Divide your article into clearly defined sections. Each subsection is given a brief heading. Each heading should appear on its own separate line. Subsections should be used as much as possible when cross-referencing text: refer to the subsection by heading as opposed to simply 'the text'.

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State the objectives of the work and provide an adequate background, avoiding a detailed literature survey or a summary of the results.

Material and methods

Provide sufficient details to allow the work to be reproduced by an independent researcher. Methods that are already published should be summarized, and indicated by a reference. If quoting directly from a previously published method, use quotation marks and also cite the source. Any modifications to existing methods should also be described.

Theory/calculation

A Theory section should extend, not repeat, the background to the article already dealt with in the Introduction and lay the foundation for further work. In contrast, a Calculation section represents a practical development from a theoretical basis.

Results

Results should be clear and concise.

Only in case of short communications, the results and discussion sections may be combined. Results should usually be presented in graphic or tabular form, rather than discursively. There should be no duplication in text, tables and figures. Experimental conclusions should normally be based on adequate numbers of observations with statistical analysis of variance and the significance of differences. The number of individual values represented by a mean should be indicated.

Discussion

This should explore the significance of the results of the work, not repeat them. A combined Results and Discussion section is often appropriate. Avoid extensive citations and discussion of published literature.

Speculative discussion is not discouraged, but the speculation should be based on the data presented and identified as such.

In most cases a discussion of the limitations is appropriate and should be included in this section of the manuscript.

Conclusions

The main conclusions of the study may be presented in a short Conclusions section, which may stand alone or form a subsection of a Discussion or Results and Discussion section.

Appendices

If there is more than one appendix, they should be identified as A, B, etc. Formulae and equations in appendices should be given separate numbering: Eq. (A.1), Eq. (A.2), etc.; in a subsequent appendix, Eq. (B.1) and so on. Similarly for tables and figures: Table A.1; Fig. A.1, etc.

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2. Empirical

Psychological Inflexibility, Somatisation and the Impact of Non-Epileptic Attack Disorder on a Person's Life

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Lancaster University Doctorate in Clinical Psychology

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Abstract

Background: There is no clear understanding of what causes and maintains non-epileptic attack disorder (NEAD), or which psychological therapies may be helpful. The relationships between variables of psychological inflexibility: experiential avoidance (EA), cognitive fusion (CF), mindfulness, and key outcome variables in NEAD: somatisation, impact upon life and non-epileptic attack (NEA) frequency were investigated.

Method: 285 individuals with NEAD participated in an online observational study. Linear regression was used to explore somatisation and impact upon life. Ordinal regression and Kruskal-Wallis tests were used to explore the variables of interest in regard to NEA frequency.

Results: EA, mindfulness, CF, somatisation and impact upon life were all significantly correlated. NEA frequency was only correlated with somatisation, impact upon life, and mindfulness. Only mindfulness was considered to uniquely predict somatisation when considered in a model with EA and CF. Impact upon life was predicted by EA, somatisation, and NEA frequency, however not by CF or by mindfulness. Individuals who have more NEAs experience higher levels of somatisation and find NEAD impacts upon their lives more significantly. Post-hoc analysis indicated that the relationships between CF and somatisation, and EA and somatisation are fully mediated by mindfulness.

Conclusions: Somatisation is a key aspect of NEAD. Mindfulness is associated closely with somatisation and EA is associated with impact upon life as well as mindfulness and somatisation. Interventions which tackle avoidance and increase mindfulness, such as acceptance and commitment therapy, may be beneficial for individuals with NEAD. Future directions for research are suggested as the results indicate more research is needed.

Psychological Inflexibility, Somatisation and the Impact of Non-Epileptic Attack Disorder on a Person's Life

Non-Epileptic Attack Disorder

Non-epileptic attacks (NEAs) are medically unexplained paroxysmal attacks which look like epileptic seizures. However, upon investigation, no epileptiform discharges can be found (Brown & Reuber, 2016b; Francis & Baker, 1999). Non-epileptic attack disorder (NEAD) is as, if not more, debilitating than epilepsy, with individuals with NEAD having lower health related quality of life (Ilic, 2013; Szaflarski, Hughes, et al., 2003). NEAD is not only distressing to the individual, but also their family members (Karakis et al., 2014), and involved medical professionals (Maatz, Wainwright, Russell, Macnaughton, & Yiannakou; Rashid, 2015). This high level of systemic distress is in part because of the stigma which surrounds medically unexplained symptomology (Sowińska, 2018). In addition, the nature of the NEAs themselves can increase distress, as they can cause additional injuries and impact an individual's ability to work, drive, and engage in leisure activities (Szaflarski, Szaflarski, et al., 2003). NEAs are most likely caused, or otherwise influenced, by psychological factors as opposed to unknown organic physiopathology (Bodde et al., 2009). Compared to individuals with epilepsy, individuals with a diagnosis of NEAD report more childhood sexual abuse (Sharpe & Faye, 2006), higher rates of trauma (Brown & Reuber, 2016a), greater levels of anxiety and depression, (Green, Norman, & Reuber, 2017; Karatzias et al., 2017), more insecure attachment styles (Brown et al., 2013), increased interpersonal difficulties (Okoye, 2014), lower health-related quality of life (Szaflarski, Szaflarski, et al., 2003), more medically unexplained

symptomology (McKenzie, Oto, Graham, & Duncan, 2011), and greater emotional regulation difficulties (Urbanek, Harvey, McGowan, & Agrawal, 2014).

The exact mechanisms of how NEAD develops and is maintained are unknown (Brown & Reuber, 2016a, 2016b). It has been suggested that this is perhaps due to there being different phenotypes within NEAD, each with unique aetiologies, attracting different psychiatric labels (Bodde et al., 2013; Brown et al., 2013; Tallentire, 2015). Whilst there is some empirical evidence which indicates that NEAD can be deconstructed further based on individual history, emotional regulation style or psychiatric diagnosis (Tallentire, 2015), there is no consensus as to what these sub-categorisations should be. Moreover, there is evidence to suggest that there are processes common across the NEAD population, such as somatisation, dissociation, and avoidance (Brown & Reuber, 2016a).

Somatisation, which is the presence of physical symptomology resulting from psychological distress rather than from a biological cause (Burton, 2003), is highly associated with NEAD. Individuals with NEAD report somatic complaints in addition to NEAs (Dimaro et al., 2014; Owczarek, 2003; Wolf et al., 2015) and somatisation distinguishes individuals with NEAD from those with epilepsy more reliably than psychiatric diagnosis, or dissociation (Reuber, House, Pukrop, Bauer, & Elger, 2003). Compared to those with epilepsy, individuals with NEAD focus significantly more on bodily sensations, attributing physical sensations more readily to illness, and experience more negative physical sensations (Owczarek, 2003). Higher levels of somatisation contribute to the decreased quality of life observed in individuals with NEAD, compared to individuals with epilepsy (Wolf et al., 2015b). Higher levels of somatisation are correlated

with poorer outcomes, with individuals experiencing more NEAs and a decreased ability to work (Reuber, House, et al., 2003).

NEAD is still a poorly understood phenomenon and there is debate as to how it can best be explained and understood. Brown and Reuber (2016b) specify four key theoretical premises which have previously been identified as contributing to the development and maintenance of NEAD. The first identifies NEAs as being triggered by dissociation linked with trauma. The second is the idea of a biological response, specifically a physiological response such as panic, without the psychological experience of panic. The third is the idea of NEAs being a form of expression of emotional distress. Finally, NEAs are proposed to be a consequence of learned behaviour (Brown & Reuber, 2016). None of these theories have been fully substantiated empirically nor can they explain what it is that creates the physical manifestation of an NEA.

Drawing on these premises, Brown and Reuber (2016b) posit a theoretical integrative cognitive model of NEAD which can be applied to all individuals experiencing NEAs. In this model, a cognitive representation of an NEA, the 'seizure scaffold,' is activated when individuals experience internal or external triggers, such as trauma memories, hypo/hyper arousal, and daily stressors which lead the individual to identify a seizure risk (Brown & Reuber, 2016b). The seizure scaffold is a cognitive blueprint of the NEA which has been established through past experiences. Once a trigger has been identified, individuals then anticipate a seizure, which in turn activates the seizure scaffold. Following the activation of a seizure scaffold, it is a deficit in inhibitory processing which causes the NEA (the physical manifestation of the seizure scaffold).

Psychological Support for Individuals Experiencing NEAD

Without psychological intervention, individuals with a diagnosis of NEAD have a poor prognosis with 71.2% of individuals continuing to have NEAs four years after their initial diagnoses (Reuber, Pukrop, et al., 2003). Psychological therapy is recommended (Carlson & Nicholson Perry, 2017; Doss & LaFrance, 2016; LaFrance et al., 2014; LaFrance, Rusch, & Machan, 2008; Mayor, Smith, & Reuber, 2011). Meta-analysis of 13 studies comprising 228 individuals with NEAD indicates that psychotherapy (including psychoeducation, cognitive behavioural therapy [CBT], psychodynamic interpersonal therapy, and mindfulness) can reduce NEA frequency, with 47% of individuals being NEA free following treatment, and 82% seeing a reduction of 50% or more in NEA frequency following intervention (Carlson & Nicholson Perry, 2017). Although this demonstrates some improvements for individuals with NEAD, the evidence is not overwhelmingly positive, with over 50% of individuals continuing to experience attacks following intervention. In addition, there is no clear psychotherapy which has been found to be more beneficial than others (Carlson & Nicholson Perry, 2017). Moreover, NEAD is a highly heterogeneous construct (Brown et al., 2013; Tallentire, 2015) and some individuals may be better supported by different or integrative therapeutic interventions (Carlson & Nicholson Perry, 2017; Cope, Poole, & Agrawal, 2017).

Acceptance and Commitment Therapy

Third wave CBTs, which focus on the relationship with thoughts, opposed to the content of thoughts, have been demonstrated to be helpful to individuals with a diverse range of difficulties (Öst, 2008). One approach, focusing on acceptance of internal experiences and mindfulness, defined as “paying attention with flexibility, openness and

curiosity" (Harris, 2009, p. 8), that has been identified as promoting positive outcomes across a range of disorders is acceptance and commitment therapy (ACT; Lappalainen et al., 2007; Morley, Williams, & Hussain, 2008). ACT is based on relational frame theory (RFT; Hayes, 2004). RFT is based on behaviourist principles and suggests that language is central to perception, with language creating the basis for how individuals view their realities and frame their experiences. This association between language and cognition establishes a mechanism for cognitive-linguistic entanglement (Hayes, Barnes-Holmes, & Roche, 2001). RFT suggests that language creates a way of understanding within relational frames, creating the bedrock for humans to be able to link and extrapolate pieces of knowledge beyond what is directly learnt. It is in this way that humans can make sense of the world. However, when these frames are overly fixed, individuals will not only learn that a threatening event should be feared, but that the thought of the event should be feared. The further consequence of this process is that strategies and cognitive styles are then employed as they are believed to be required to prevent the experience of distress, resulting in psychological inflexibility (Fletcher & Hayes, 2005; Hayes, 2004).

Psychological inflexibility occurs when individuals perceive that they are unable to change their internal or external behaviour to be in accordance with their own desires and values. Psychological inflexibility is comprised of six key components: experiential avoidance (EA), cognitive fusion (CF), attachment to the conceptualised self, dominance of the conceptualised past and future, lack of values, clarity and unworkable action (Harris, 2009). All components of psychological inflexibility are interrelated, yet all also contribute to psychological distress independently (Harris, 2009; Hayes, 2004). EA is the repudiation of private experiences as these experiences are viewed as distressing. CF is the over

entanglement with thoughts, to the point where they dominate awareness and behaviour. When individuals have high levels of CF they will experience their thoughts as absolute truths and therefore thoughts must be responded to, it is in this way that CF allows behaviour to be unhelpfully dominated by private experiences. CF and EA can then create a cognitive loop whereby individuals are focusing and ruminating on their thoughts, leading to an over-dominance of the conceptualised past. This then prevents individuals from having contact with their values, as they are stuck in this cycle. Workable action is similar, where cognitive processes promote an unhelpful pattern of thoughts and behaviours, which often feels uncontrollable to the individual. The final component of psychological inflexibly is attachment to the conceptualised self, which is the idea that individuals are overly fused with the narrative of who they are and this promotes a rigid pattern of behaviour and a set of overly constrictive guidelines on how one must engage with the world (Harris, 2009).

ACT conceptualises all psychological distress, regardless of psychiatric label, as resulting from psychological inflexibility. The goal of ACT is then to increase flexibility, rather than focus on symptom reduction. Psychological inflexibility is then targeted through increasing acceptance via mindfulness and cognitive techniques to ultimately change an individual's relationship with their thoughts, thereby re-instilling the perception of choice and agency (Fletcher & Hayes, 2005) and allowing one to live a mindful, value-aligned life. All components of psychological inflexibility are thought to be highly related and interconnected constructs. Despite this, they are all still believed to uniquely contribute to psychological distress (Hayes, Levin, Plumb-Vilardaga, Villatte, & Pistorello, 2013).

ACT and NEAD

Components of psychological inflexibility may be theoretically important within the construct of NEAD, considering Brown and Reuber's (2016b) model. Three key components of psychological inflexibility, which seemed theoretically relevant in NEAD, were identified: CF, EA, and being in contact with the present moment, also known as mindfulness. The seizure scaffold was believed to link with CF, as it appears likely that individuals who have higher levels of CF will be entangled with the mental representation of an NEA, feeling it to be a real and true event to which they must respond (Hayes, 2004). However, to date CF has not been explored in the NEAD population. This need to respond, based on the concept that thoughts are the same as the events themselves, could theoretically initiate the physical manifestation of a 'seizure' as individuals would be likely then to fear the thoughts of an NEA. Individuals with NEAD then possibly engage in EA to try to avoid such sensations (Cope et al., 2017). Engaging in EA can paradoxically intensify and strengthen unwanted thoughts (Hayes, 2004). If thoughts of NEAs are feared then individuals are likely try to suppress the thought of a seizure and/or the feelings and thoughts surrounding a trigger. Consequently, attempting to suppress thoughts of seizures, or unwanted feelings, may instead strengthen the association between the thoughts and the 'seizure scaffold'. Thus, it seems possible that EA may perpetuate CF and CF in turn perpetuates EA. It is at this point that mindfulness may become important.

Finally, levels of mindfulness may be important, as practising mindfulness gives individuals cognitive skills which allows individuals the freedom to decide how to respond to thoughts (Hayes, 2004). By increasing individuals' ability to select how they respond to cognitions, individuals may be able to employ strategies to prevent the NEA from

occurring (Cope et al., 2017), eventually weakening the link between the 'seizure scaffold' and the physical manifestation of an NEA (Brown & Reuber, 2016b). The evidence that mindfulness contributes to cognitive skills which are implicated in being able to choose how to respond to thoughts, comes from research on mindfulness and the executive function of inhibition. Inhibition relates to the ability to inhibit or prevent previously learnt rules or sets. Intact inhibitory processes allow an individual to choose how to respond, as opposed to responding in the way which has been previously learnt. Mindfulness has been demonstrated to improve inhibition (Gallant, 2016). Brown and Reuber (2016b) suggest that individuals with NEAD have a deficit in inhibitory processing which gives the individual no option but to succumb to the overwhelming urge of the seizure scaffold. Therefore, it is theoretically possible that a lack of being able to choose how to respond to thoughts may result in increased, yet unsuccessful, attempts to prevent the thoughts of an NEA. Again, there is minimal research which explores mindfulness in NEAD; however, Baslet, Dworetzky, Perez, and Oser (2015) used a case series design to identify that mindfulness based intervention could successfully reduce NEA frequency.

While these theoretical arguments suggest key ACT concepts may be important in the development and maintenance of NEAD, to date, empirical evidence of ACT being used to support people with NEAD is highly limited (Cope et al., 2017). Baslet (2011) published a case study in which ACT was successfully used to support a 31-year-old woman experiencing NEAD to reach her goals and reduce her somatic symptoms. Although the empirical evidence is limited, there is a strong rationale to consider ACT to support individuals with NEAD. Cope et al. (2017) identified that ACT may be beneficial to support individuals with NEAD, suggesting that the mindfulness component of ACT can

build mind-body awareness and aid individuals with NEAD in noticing the early stages of an NEA. They then may be able to use strategies to prevent the NEA from occurring. Shifting from avoidance to acceptance of internal experiences can reduce distress associated with internal experiences and individuals are more able to choose how they respond to such experiences (Hayes, 2004). Cope et al. (2017) suggest that this would be particularly beneficial with NEAD, due to the focus on distressing physical experiences, providing individuals with the ability to decide how to respond to such events. Although there is no methodologically robust empirical evidence for the use of ACT to support individuals with NEAD, there is substantial evidence of ACT being used to support individuals with other medically unexplained presentations such as chronic pain (Hann & McCracken, 2014) and irritable bowel syndrome (Sebastián Sánchez et al., 2017). In addition, two randomised control trials indicated that ACT effectively reduces seizure frequency in epilepsy and lessens the impact of epilepsy upon individuals' quality of life (Lundgren, Dahl, Melin, & Kies, 2006; Lundgren, Dahl, Yardi, & Melin, 2008). Furthermore, ACT has been found to be more beneficial than traditional CBT for individuals who exhibit high levels of avoidance (Davies, Niles, Pittig, Arch, & Craske, 2015), a psychological strategy highly utilised within the NEAD population (see Section 1).

Research Aims and Questions

In summary, there is reason to believe that the three components of psychological inflexibility described above (EA, CF and mindfulness) might be particularly relevant to the genesis and maintenance of NEAD in accordance with Brown and Reuber's (2016b) model. The aim of the current study was to determine whether EA, CF, and mindfulness

would predict key NEAD variables. There is no easily identifiable or reliable outcome measure for NEAD (Reuber, Mitchell, Howlett, & Elger, 2005). NEA remission is often used, however, Reuber et al. (2005) suggest that this is too narrow. Unlike individuals with epilepsy, 'seizure' frequency is not a clear indicator of quality of life and productivity for individuals with NEAD. Somatisation has been identified as an integral component of NEAD (Owczarek, 2003; Reuber, House, et al., 2003) and Wolf et al. (2015) suggest somatisation reduction should be included as a focus of psychological support for individuals with NEAD. Therefore, the present study focusses on impact upon life, NEA frequency, and somatisation as dependent variables.

Three research questions were asked. I) What are the relationships between CF, EA, mindfulness, and somatisation in NEAD? It was hypothesised that higher levels of CF, EA, and lower levels of mindfulness would all be correlated with somatisation and these variables would independently predict somatisation. II) Do the psychological inflexibility variables, NEA frequency and somatisation predict perceived impact of life within the NEAD population? It was hypothesised that all variables would be significantly correlated and that higher levels of EA, CF, and somatisation, higher NEA frequency and lower levels of mindfulness would relate to more impact upon life within the NEAD population. It was also hypothesised that all factors would independently predict impact upon life. III) Do mindfulness, EA, CF, and somatisation predict NEA frequency? It was hypothesised that individuals with higher levels of somatisation, CF and EA, and lower levels of mindfulness would experience more frequent NEAs. Due to the exploratory nature of this study, probing post-hoc analyses were conducted exploring the relationships between some of the

variables to promote further research questions. Post-hoc analysis must be considered with caution; these analyses were conducted only to identify areas of future research.

Methods

Design

An online single group cross-sectional observational design was used. All questionnaires were posted on-line using Qualtrics, digital survey software (Qualtrics, Provo, UT). An online recruitment strategy was selected so as to reach a wide variety of individuals at reduced cost and burden to both participant and researcher (King, O'rourke, & DeLongis, 2014). Service users, accessed through NEAD charities, were consulted throughout the design phase of this project. Lancaster University's Faculty of Health and Medicine Research Ethics Committee approved the project in August 2017 (see Section 4).

Participants

Participants were 285 individuals who identified as having a diagnosis of NEAD. They were recruited between August 21st 2017 and January 7th 2018. The link to the survey was posted on Twitter, and NEAD Facebook groups by the lead researcher; also, charities supporting individuals with NEAD posted the link on their websites and social media platforms (Facebook and Twitter). Of the 425 individuals who clicked on the link to participate in the survey, 331 people consented to participate in the study, 29 of these people did not begin the study (completed less than one questionnaire) and the remaining 17 individuals were missing one or more entire questionnaires and were therefore excluded from the final analysis.

Analysis

All analyses were conducted using IBM SPSS version 23. Descriptive characteristics of the data were explored and reported. To understand the relationships between the variables under investigation univariate correlations were conducted using Spearman's rank-order correlation. Spearman's rank-order correlations were conducted as none of the variables of interest were normally distributed (see Appendix 2-A). In addition, this allowed for the inclusion of ranked variables. To explore the research questions in more depth, regression analyses were conducted for each of the dependent variables: somatisation, impact upon life, and NEA frequency. The first two research questions were explored using backwards hierarchal multiple linear regressions. Predictor variables were the variables of interest, along with any potential confounding variables which were significantly correlated with the outcome variable. The first backwards hierarchal multiple linear regressions had somatisation as the dependent variable and CF, EA, mindfulness, gender, as predictors. The second had impact upon life as the outcome and somatisation, CF, EA, mindfulness, and NEA frequency, as predictors. The third research question was explored using ordinal regression with NEA frequency as the dependent variable and CF, EA, mindfulness, and somatisation as independent variables. To correct for family-wise type one error rate, Holm-Bonferroni corrections were applied. Mean imputation was used as there was less than 0.5% of the data missing, with no consistent patterns, therefore multiple imputation was not necessary (Schafer, 1999). All analyses were adequately powered as an a priori power analysis identified a sample size of 107 would have an 80% chance of detecting a medium effect, at $p < .05$.

The results of the a priori analyses identified that the relationships between variables of psychological inflexibility within NEAD are complex and these constructs are likely inter-related in a multi-directional manner. Therefore, post-hoc explorations of the data were conducted to gain further insight into the relationships. Post-hoc explorations were based upon the observed data as well as Brown and Reuber's (2016b) model. It was thought that mindfulness may mediate the relationship between EA, CF and somatisation. First, to explore if EA and CF predicted levels of mindfulness, a forced entry linear regression was conducted with mindfulness as the dependent variable. To check if mindfulness mediated the relationship between CF, EA, and somatisation, two post-hoc mediation analyses were conducted using PROCESS (Hayes, 2017) version 3.0 using 5000 bootstrapping. In the first mediation, EA was placed as the predictor variable, gender was controlled for and mindfulness was placed as the mediator with somatisation as the dependent variable. The second mediation followed the same structure except EA was replaced by CF as the predictor variable.

Materials

Physical Health Questionnaire -15 (PHQ-15; Spitzer, Kroenke, Williams, & Group, 1999). The PHQ-15 is a 15-item measure of somatisation and physical symptoms. Participants are asked to rate how much they have been bothered (not at all bothered, bothered a little, bothered a lot) by specific physical symptoms over the last four weeks. A total score is then calculated. The PHQ-15 has been administered to numerous populations (Kroenke, Spitzer, Williams, & Löwe, 2010) including the NEAD population (Dimaro et al., 2014). It has an acceptable internal consistency of α=.79 (Kroenke, Spitzer, & Williams, 2002) and has been recommended as the best tool to measure somatic

symptomology (Sitnikova, Dijkstra-Kersten, Mokkink, Terluin, & Van Der Wouden, 2017). The PHQ-15 provides ratings of severity, based upon a normative sample of 6000 randomly selected primary care patients, with less than five indicating mild somatising symptoms, between five and nine as moderate and ten or greater as being severe.

Acceptance and Action-two Questionnaire (AAQ-II; Bond et al., 2011). The AAQ-II is a seven-item scale which measures EA. Participants are asked to rate how true statements such as "I'm afraid of my feelings" are from one (never true) to seven (always true). A total summation score is given with higher scores reflecting higher levels of experiential avoidance. The AAQ-II has been previously used to measure experiential avoidance within the NEAD population (Baslet, Tolchin, & Dworetzky, 2017). It is a reliable measure, having a mean α coefficient of .84 and a 12-month test- retest reliability of .79. The AAQ-II has been found to have acceptable divergent and convergent validity (Bond et al., 2011).

Mindful Attention Awareness Scale (MAAS; Brown & Ryan, 2003). The MAAS has 15-items and it is a reliable, valid and useful measure of mindfulness (Brown &Ryan, 2003; MacKillop & Anderson, 2007). There are different operationalisations of mindfulness within the literature. The MAAS has been used to measure mindfulness broadly, however it is considered to tap into the construct of dispositional mindfulness or mindful awareness (MacKillop & Anderson, 2007). Participants are asked to rate how frequently they experience each item on a six-point Likert scale (1= almost always, 6=almost never). Items ask about how aware a participant is in their daily life, such as "I do jobs or tasks automatically, without being aware of what I'm doing.". The score is the mean of all the items, with higher scores indicating higher levels of dispositional

mindfulness. It has been used across a wide variety of populations and has good convergent and divergent validity (Brown & Ryan, 2003). The MAAS has good internal consistency with a reported Cronbach's α of .89 (MacKillop & Anderson, 2007)..

Cognitive Fusion Scale (Gillanders et al., 2014). The CFS has a similar structure to that of the AAQ-II, it is a seven-item measure which asks participants to rate how true each statement is on a seven-point Likert scale. The CFS measures the construct of cognitive fusion asking statements such as "I tend to get very entangled in my thoughts". This scale has been shown to differentiate significantly between distressed and non-distressed samples. This scale has also been found to have a good internal consistency with a reported Cronbach's α of .88 in a mixed mental health sample and .90 in a community sample. Test-retest reliability is .80 (Gillanders et al., 2014)**.**

Demographic information and diagnosis information. A bespoke demographic and diagnosis information questionnaire was used in this study. Questions such as age, how diagnosis was made, as well as working status, education and ethnicity were asked see Section 4 for a copy of this questionnaire. The researcher developed this measure based on information which has been deemed important within this population based upon previous research, clinical expertise and service user input. As part of the demographic questionnaire, individuals reported upon NEA frequency, indicating if they had NEAs daily, weekly, monthly, yearly, or not currently experiencing NEAs.

Work and Social Adjustment Scale (WSAS; Mundt, Marks, Shear, & Greist, 2002). The WSAS is a five-item scale which uses a zero to eight Likert scale to identify how much an individual finds their difficulties impact their life. The questions pertain to areas of leisure, work, social and home functioning. The scale is frequently used in mental

health out-patient services and has been validated to be used with a wide variety of populations within the UK. The WSAS has an acceptable to good internal consistency with Cronbach's α ranging from .7-.9 (Mataix-Cols et al., 2005).

Results

Demographic and Descriptive Information

Of the 285 participants included within the data analysis, 210 reported diagnostic confirmation via video telemetry, the gold standard for diagnosing NEAD (Angus-Leppan, 2008). Thirty individuals stated that their diagnosis had been made in hospital but it was unclear how this diagnosis had been made, 17 stated that their diagnosis was made using MRI, 18 stated that their diagnosis was given by a medical professional such as a neurologist or psychiatrist, and finally 10 participants did not disclose how they received a diagnosis of NEAD. The majority (n=247, 86.7%) of participants identified as female, with an age range of 18-72 years (mean=38.16, SD=12.02). An international sample was used with most participants (n=275) coming from English speaking western counties and identifying as white (n=211, 74.0%), refer to Table 1 for further details.

INSERT TABLE 1

Forty (14.0%) of the participants identified as having concurrent epilepsy. There were no significant differences between the group with concurrent epilepsy and those with NEAD only on any of the variables of interest ($p>.05$, see Appendix 2-B). Therefore, individuals with concurrent epilepsy were included within the analysis. Most of the sample (n=227, 79.6%) identified as having a diagnosed mental health difficulty such anxiety, depression, bipolar disorder, or post-traumatic stress disorder. As would be expected, individuals who identified as having a mental health diagnosis had statistically significant

decreased psychological flexibility (higher CF, higher EA, lower levels of mindfulness), and higher somatising.

Normality of all variables of interest (mindfulness, EF, EA, somatisation, impact upon life) was explored using a Shapiro-Wilk test (see appendix 2-C). All variables were found to be significantly different from a normal distribution ($p<.05$). Therefore, medians and inter-quartile ranges (IQR) were reported. Data were reported from the psychological variables overall as well as per NEA frequency category. The highest medians for EA, somatisation, and impact upon life were seen in the daily category of NEA frequency. The lowest median for mindfulness (least mindful) was seen in the weekly category, and the highest median for CF was seen in the monthly category. See Table 2.

INSERT TABLE 2

Somatising

The scores on the PHQ-15 ranged from 1-30, with a median of 15.00 (IQR=7). Within the sample, internal consistency was acceptable (Cronbach's Alpha =.78). The majority of the sample (88.2%) fell within the severe range, and less than one percent (.7%) of the sample fell within the mild range (Kroenke et al., 2010). Three or more symptoms identified as "bothered a lot" has been identified as a good means to identify individuals whom meet the criteria for a somatoform disorder according to Diagnostic and Statistical Manual -IV TR (American Psychiatric Association, 2000), with 71% specificity and 78% sensitivity (van Ravesteijn et al., 2009). Again, most of the sample (82.5%) endorsed three or more symptoms as "bothered a lot" during the past four weeks. For correlation, regression and post-hoc investigations, two questions were excluded from the PHQ-15 total score. The first was the question which asks about fainting spells, as it was thought this

related directly to experiencing NEAD and therefore may inflate the PHQ-15 scores. Question D, which asks about menstruation, was also excluded as this question only applies to women, and the PHQ-15 is a summated raw score. It was therefore thought that the inclusion of this question may artificially inflate the impact of gender upon somatisation. Following the removal of these items the median was 14.00 (IQR=6.5). Internal consistency was still acceptable (Cronbach's α=.76).

Impact Upon Life

The WSAS was used to identify the individuals' perceived impact of their NEAD upon their life. The internal consistency for the scale was found to be good (Cronbach's α= .87). The largest impact of NEAD was on the individuals' ability to work with a median score of 7, which equates to a categorisation between "definitely impacts" to "markedly impacts". NEAD impacted the least upon individuals' ability to engage and maintain close relationships and private leisure activities, both with a median score of 4 placing it within the "definitely impacts" categorisation. Total scores of the WSAS ranged from zero to forty with a median of 25.00 (IQR=16.50). Most of the sample (68.4%) reported scores which placed them in the severe categorisation of the WSAS, whereas only 10.2% of the sample reported scores which placed them within the low rating on the WSAS.

Experiential Avoidance

The AAQ-II was found to have a good internal consistency (Cronbach's α =.94). Within the sample scores ranged from 7-49. The median total score was 32.00 (IQR=18.00).

Cognitive Fusion

The CFQ had an excellent internal consistency (Cronbach's α =.94). As with the AAQ-II, the full range of scores was obtained (7-49). The median total score was 34.00 (IQR=15.00).

Mindfulness

The MAAS was found to have a good internal consistency (Cronbach's α = .88). The total mean scores ranged from 1.13 -5.87, with a medium 3.33 (IQR=1.33).

NEA Frequency

NEA frequency was defined by four categories: daily attacks, weekly but not daily, monthly but not weekly, yearly but not monthly, and not currently having attacks.

Correlations

To explore the relationship between the variables of interest, as well as possible confounding variables, Spearman's rank correlation was conducted, as none of the variables were normally distributed, and this allowed for inclusion of ordinal variables (see Table 3). Significant correlations were found between somatising, mindfulness, CF, EA, impact of NEAD on the individual's life, with effect sizes ranging from medium to large. NEA frequency was significantly correlated with somatisation, mindfulness, and impact upon life. Sex was only significantly correlated with somatisation, and age was only found to significantly correlate with CF.

INSERT TABLE 3

Research Question One: What are the Relationships between CF, EA, levels of Mindfulness, and Somatisation in NEAD?

To further explore the first research question, 'What are the relationships between CF, EA, levels of mindfulness, and somatisation in NEAD?' regressions were conducted with somatisation as the dependent variable. All possible confounding variables which had a significant correlation with somatisation were entered into the regression. The dependent variable was the total summed score on the PHQ-15, excluding the two questions noted above. Assumptions of: linearity, multivariate normality, homoscedasticity, independence of errors, and no-multicollinearity (Field, 2013) were all met (see Appendix 2-C). Variables were entered into a hierarchal backwards multiple regression. Variables entered were, gender, EA, CF, and mindfulness. All models were found to be significant. Two variables were retained in the final iteration of the model, being female, and levels of mindfulness ($F(2,282) = 53.513$, $p < .0005$ adj $R^2 = .270$.). Only mindfulness was found to be a significant unique predictor of somatisation. See Table 4 for regression models.

INSERT TABLE 4

Post-Hoc Analysis

A forced entry linear regression was conducted with mindfulness as the outcome variable and EA and CF as the predictors, whist controlling for gender. A significant regression equation was found $F(2,282) = 50.856$, $R^2 = 40.1$, $p < .0005$ and both EA and CF were retained as significant independent predictors (EA: $b = -.024$, $p < .0005$; CF: $b = -.033$, $p < .0005$). Two separate mediation analyses were conducted using 5000 bootstrapping. One with EA as the predictor variable, mindfulness as the mediator, and with somatisation

as the dependent variable, whilst controlling for gender. The other with the same structure with CF as the predictor variable. Mindfulness was found to fully mediate the relationship between both EA and CF with somatisation. EA was an independent predictor of mindfulness (b=-.0487 SE=.0038, p<.00005, 95% CI[-.0561, -.0412]) and EA was a significant predictor of somatisation (b=.1453, SE=.0217, p=.00005, 95% CI[.1025, 1880]). However, EA was no longer a significant predictor after controlling for the mediator, mindfulness, (b=.0383, SE=.0253, p=.1307, 95% CI[-.0114, .0881]). Similarly, mindfulness fully mediated the relationship between CF and somatisation whilst controlling for gender, as CF was found to predict mindfulness, (b=-.0566, SE=.0043, p<.0001, 95% CI[-0.651, -0.481]) and somatisation (b=.1649, SE=.0259, p=.00005, 95% CI[1157, .2141]), however was no longer a significant predictor when mindfulness was entered as a mediator (b=.0386, SE=.0293, p=.1883, 95% CI[-.0190, .0963]).

Research Question Two: Do the Psychological Inflexibility Variables, NEA Frequency and Somatisation Predict Perceived Impact of Life within the NEAD Population?

A backward linear regression was conducted to explore the second research question, 'Do the psychological inflexibility variables, NEA frequency and somatisation predict perceived impact of life within the NEAD population?'. Assumptions of: linearity, multivariate normality, homoscedasticity, independence of errors, and no-multicollinearity were met (see Appendix 2-D). The final model retained five significant predictors of impact upon life: daily NEAs, weekly NEAs, monthly NEAs, somatisation, and EA, which explained 33.1% of the variance ($F(8,276)=18.350$, $p<.0005$, adj $R^2=.331$). See Table 5 for the regression coefficients.

To further explore the impact upon life in relation to NEA frequency, a Kruskal-Wallis test was conducted, with all subsections of the WSAS. Variables were not normally distributed and therefore the assumptions for parametric analysis were not met. The significance was set at 95% using the Monte Carlo method. Significant differences were found, with individuals with higher frequency NEAs experiencing more total impact upon life ($\chi^2(4)=38.966$, p=.0005), impact upon work ($\chi^2(4)=35.0897$, p=.0005), impact upon home management $\chi^2(4)=31.119$, p=.0005), impact upon social leisure activities ($\chi^2(4)=30.009$, p=.0005), impact upon private leisure activities ($\chi^2(4)=27.564$, p=.0005) and impact upon personal relationships ($\chi^2(4)=15.865$, p=.003). All maintained significance once Holm-Bonferroni corrections were applied.

INSERT TABLE 5

Research Question Three: Do Mindfulness, EA, CF, and Somatisation Predict NEA Frequency?

To the third research question 'Do mindfulness, EA, CF, and somatisation, predict NEA frequency?' a cumulative odds ordinal logistic regression was run to determine the effect of CF, mindfulness, EA, and somatisation on NEA frequency. The assumptions of proportional odds (full likelihood ratio test $\chi^2(12)=19.235$, P>.05) and no multicollinearity were met (see Appendix 2-E). Cells were sparse as 80% had zero frequencies, therefore goodness of fit was determined by comparing the final model's ability to predict the dependent variable compared to the intercept-only model, a statistically significant difference was found ($\chi^2(4)=17.380$, p=.002). An increase in somatisation was associated with an increase in the odds of having more NEAs, with an odds ratio of 1.093, 95% CI[1.035, 1.154], $\chi^2(1)=10.220$, p=.001. An increase in CF was associated with a decrease

in the odds of having more NEAs with an odds ratio of .956, 95% CI=[.917,996], $\chi^2(1)=1.653$, p=.031. Neither EA nor mindfulness were significantly associated with predicting an increase in NEA frequency. See Table 6.

INSERT TABLE 6

Discussion

This exploratory study aimed to investigate the relationship between variables related to psychological inflexibility (CF, EA and mindfulness) and variables that are considered key outcome variables within NEAD. Three outcome variables, somatisation, impact of NEAD upon life, and NEA frequency were chosen as there is not a clear indication of what denotes a beneficial outcome in NEAD (Reuber et al., 2005). Three research questions were specified. I) What are the relationships between CF, EA, levels of mindfulness, and somatisation in NEAD? II) Do the psychological inflexibility variables, NEA frequency and somatisation predict perceived impact of life within the NEAD population? III) Do mindfulness, EA, CF, and somatization predict NEA frequency?

The variables of interest: CF, EA, and mindfulness are highly related and yet distinct concepts, all thought to uniquely contribute to psychological distress (Fletcher & Hayes, 2005; Hayes, 2004; Palladino et al., 2013). A large significant and positive correlation was found between CF and EA. CF and EA both correlated with mindfulness with lower levels of mindfulness being related to higher levels of both EA and CF. The correlations found between CF, EA and mindfulness were higher than had previously been identified (Palladino et al., 2013).

Research Question One: What are the Relationships between CF, EA, levels of Mindfulness, and Somatisation in NEAD?

The first hypothesis was that EA, CF, and mindfulness would be correlated with somatisation and would independently predict somatisation when entered into a regression model together. The findings of this study were somewhat consistent with the hypothesis and are congruent with previous research. Congruent with previous literature, high levels of somatisation, in addition to the presence of NEAs, were found within the present sample. Most individuals fell within the severe range of somatisation (Owczarek, 2003; Peveler, Kilkenny, & Kinmonth, 1997; Reuber, House, et al., 2003; Wolf et al., 2015). Higher levels of EA, CF and lower levels of mindfulness were all associated with higher levels of somatisation. This is also consistent with research which indicates that higher levels of EA and lower levels of mindfulness are associated with higher levels of somatisation (Masuda, Mandavia, & Tully, 2014). However, in contrast to both the hypothesis and previous literature, only mindfulness was found to be a unique and independent predictor of somatisation when CF, EA and mindfulness when explored together. Mindfulness and EA have both been found to be unique independent significant predictors of somatisation within the general population (Masuda & Tully, 2011). This is possibly due to the inclusion of CF in this model which, although the assumption of non-multicollinearity was not violated, was highly correlated with EA and possibly mitigated the unique contribution of EA. In addition, gender, although not significant, was retained in the final model of the backwards regression. This is consistent with previous literature that suggests that women have higher levels of somatisation than men (van Ravesteijn et al., 2009). This finding held true even when questions pertaining exclusively to women

were excluded from the analysis. Although there is limited research exploring NEAD (Baslet, 2011; Baslet et al., 2015) and mindfulness, there are meta-analytic data demonstrating that mindfulness-based therapies can increase quality of life and reduce symptom severity with a variety of somatising conditions (Lakhan & Schofield, 2013).

The results of this study identified that the relationships between variables of psychological inflexibility within NEAD are complex and these constructs are likely inter-related in a multi-directional manner. Therefore, post-hoc explorations of the data were conducted to gain further insight into the relationships. It is important to consider the post-hoc analysis with caution; this was conducted with the sole purpose of promoting further research questions. A regression analysis exploring if EA and CF predict mindfulness was conducted. This was done as EA and CF were very highly correlated and Gillanders et al. (2014) suggest that EA, CF and mindfulness may relate differently within different populations. However, there is no previous research exploring these three constructs within NEAD. A significant relationship was found with both EA and CF being independent predictors of mindfulness. This supports the conceptualisation that EA and CF are highly related but separate constructs within NEAD, that warrant further exploration.

Following this, a mediation analysis was conducted exploring if mindfulness mediates the relationship between both EA and CF and somatisation. This was conducted as EA and CF were found not only to be highly correlated with each other but also with mindfulness and somatisation. However, neither EA nor CF were not found to be significant independent predictors of somatisaiton when entered into a regression model alongside mindfulness. This is inconsistent with previous research which has demonstrated that EA is an important predictor of somatisation even when considered alongside

mindfulness (Masuda, Mandavia, & Tully, 2014). It was found that EA and CF both predict somatisation, however this relationship is fully mediated through mindfulness. Considering the Brown and Reuber (2016b) model, a possible explanation for this is that if people are more able to choose how they respond to internal experiences then they may not be fearful of them and avoid them. This may minimize the amount of somatisation they experience. Within NEAD, individuals may fear physical sensations (Cope, et al. 2017) and then engage in avoidance, inadvertently intensifying the sensations. However, if individuals are able to choose how they respond to such thoughts they will not engage in a pattern of avoiding these internal experiences and therefore the physical experiences of somatisation may not occur. This mediation analysis provides further evidence that mindfulness, as measured by the MAAS, may be an important mechanism within NEAD. Further exploration of mindfulness within NEAD may help to illuminate potential interventions in the future.

Research Question Two: Do the Psychological Inflexibility Variables, NEA Frequency and Somatisation Predict Perceived Impact of Life within the NEAD Population?

The second research question explored the predictive value of somatisation, mindfulness, EA, CF, and NEA frequency on the perceived impact of NEAD on an individual's life. It was hypothesised that EA, CF, mindfulness and NEA frequency would correlate with impact upon life. Again, higher levels of EA and CF along with lower levels of mindfulness were associated with NEAD having a more negative impact upon one's life. Unsurprisingly, having more NEAs was associated with having a greater impact upon an individual's life. Individuals experiencing more NEAs were found to rate the impact upon their life as significantly greater, in all areas, indicating that NEA does not only impact

individuals' ability to work, but also to engage in social-leisure activities that may be highly fulfilling and beneficial to their overall well-being. It was again hypothesised that all factors would uniquely contribute to the perceived impact of NEAD on an individual's life and again this hypothesis was not fully supported. EA, somatisation and higher NEA frequency remained independent predictors of impact upon life. The WSAS (Mundt et al., 2002) has not been used to explore impact upon life within the NEAD population previously. This finding is consistent with quality of life research which has indicated that both somatisation and NEAD can negatively impact quality of life (Wolf et al., 2015). However, CF was not found to be a significant unique predictor when considered alongside the other variables of interest. This again could be due to the high levels of correlation with EA found within this sample, as CF and impact upon life were found to be related based on univariate correlations. Furthermore, and again in contrast to the hypothesis, mindfulness was not found to be a predictor of impact upon life. Mindfulness was found to be a highly significant independent predictor of somatisation, which in turn was highly significant within the impact upon an individual's life. Therefore, mindfulness does not independently predict impact upon life above and beyond what can be explained by somatisation, EA and NEA frequency.

Research Question Three: Do Mindfulness, EA, CF, and Somatisation Predict NEA Frequency?

The third question explored which variables predicted NEA frequency. It was hypothesised that as NEAs increased in frequency, individuals would demonstrate higher levels of somatisation, EA, and CF, and have lower levels of mindfulness. The results were, again, partially consistent with the hypothesis. Having higher levels of somatisation

in areas beyond what could be directly attributable to NEAD significantly increased the odds of experiencing more NEAs. However, contrary to the hypothesis, EA and mindfulness were not associated with frequency of NEAs when considered in a model together. Levels of mindfulness were also found to correlate with NEA frequency, although this correlation was relatively small and this relationship was not found to significantly increase the odds of experiencing more NEAs.

What is interesting is that NEA frequency was predicted by somatisation and somatisation was predicted by mindfulness. Mindfulness was associated with NEA frequency at univariate level. However, contrary to expectations from the Brown and Reuber (2016b) model, mindfulness did not predict NEA frequency in the multivariate analysis. The meaning of this finding is not clear. Brown and Reuber (2016) suggested that inhibitory control is important in the translation of the thought of an NEA into its physical manifestation. However, this study did not directly explore inhibitory control but instead explored mindfulness, relying on the assumption that mindfulness is related to inhibitory control. Although we know that increasing mindfulness increases inhibitory control, we do not know as much about how these two variables correlate prior to intervention. Therefore, the lack of association of mindfulness with NEA frequency may not necessarily correspond to a lack of relationship with inhibitory control and indeed it may be an area for future research to explore inhibitory control within NEAD and the relationship that it has with mindfulness and NEA frequency.

CF was significantly associated with NEA frequency when considered alongside other variables, but the amount of variance accounted for in the correlational analysis was trivial and non-significant. This is an interesting finding which warrants further

exploration. Furthermore, the association was contrary to what was predicted, as CF was found to significantly reduce the odds of experiencing more NEAs in the regression analysis. Based on these observations, it seems highly likely that this is due to a suppressor effect. Suppressor effects occur when multiple variables which are highly related are entered as independent variables, changing the relationship the two variables have with the dependent variable. This suggests that when these variables were entered together the error term was reduced and a relationship between CF and NEA frequency was teased out (Watson, Clark, Chmielewski, & Kotov, 2013). However, suppressor effects are complex and this relationship warrants further investigation, as this may be a superfluous finding. This further indicates that more complex modelling would be beneficial to consider in future research studying the constructs of EA, CF, mindfulness, somatisation and NEA frequency.

EA was not found to correlate with or predict NEA frequency. Although this was contradictory to the hypothesis this may well reflect previous research as the findings on EA and NEA frequency have been inconsistent (Dimaro et al., 2014; Novakova, Howlett, Baker, & Reuber, 2015). This is possibly due to the way in which the NEA frequency data were obtained. Data were provided via self-report and in the categories of daily, weekly, monthly, yearly or not currently occurring. Identification of NEA frequency is not consistent across the literature. By having broad categories, the data found by this study may have missed a subtle effect as those who experienced a daily NEA would be grouped with those who experience many. Furthermore, this finding may relate to the use of a self-report as individuals with NEA are not always aware when they have experienced an NEA

and NEA may be categorised differently by different individuals and therefore may result in unreliable report.

Further consideration is required by researchers as to how best to evaluate severity of NEAD and frequency of NEAs. Clearly no one approach is entirely satisfactory and in the present study the crude categorisation for the purposes of linear modelling may have been inadequate.

Overall Findings

This study provides further evidence that somatisation is a key component of NEAD. This study also provides preliminary evidence for how factors relating to psychological inflexibility may be pertinent to somatisation. Somatisation in turn is a highly significant predictor in the perceived impact upon an individual's life and increases the odds of having more frequent NEAs. This study identified that although EA, and CF, are highly correlated with somatisation and impact upon life in NEAD, they are not correlated with NEA frequency. Furthermore, only mindfulness uniquely contributed to somatisation when EA, CF, and mindfulness were considered within a model together. Post-hoc analysis identified that EA and CF both predict mindfulness, and the relationships between both CF and EA and somatisation are fully mediated through mindfulness. Although not found to be related to an increase in odds of experiencing more NEAs, EA was found to be a unique independent predictive factor for impact upon life. This may be due to the nature of the variable, whereby people with higher levels of EA are likely to avoid work and social situations and therefore it will increase the impact upon their life (Kashdan, Morina, & Priebe, 2009).

In summary, this study provides evidence that EA, mindfulness, and somatisation are important factors within NEAD, and raises questions about CF and the interrelated nature of variables of psychological inflexibility with NEAD. Although CF was correlated with impact upon life and somatisation it was not found to be a unique predictor of either when explored in multivariate models. Nevertheless, it is possible, considering the univariate analysis, that CF is important within NEAD. However, the relationships between variables considered part of psychological inflexibility such as EA, CF and mindfulness have been questioned more broadly within the literature (Gillanders et al., 2014) and have not previously been explored within this population. It may well be that CF is important at an earlier stage of the process explored and therefore was not found to be directly related to any of the explored variables. However, due to the novel nature of this study, only cautious conclusions can be drawn and more research is needed to identify how these variables may contribute to the development and maintenance of NEAD. Somatisation may be a key route to experiencing NEAs and NEAD having a greater impact upon life. Somatisation in turn may be driven by factors associated with psychological inflexibility. This suggests that larger scale, more sophisticated analyses (path analysis/SEM) might be required in the future, so as to tease out potential explanatory models.

Limitations

There are limitations with which the results of this study must be considered. First, the nature of the study design. This study utilised an observational design and therefore causality cannot be inferred. Furthermore, the lack of a control group also makes it impossible to tell if these findings are unique to the NEAD population. The study used an

on-line recruitment strategy which can increase external validity by reaching a wide variety of participants but poses limitations as well. Indeed, there is no way to identify if individuals participating truly had a diagnosis of NEAD. NEAD is a highly stigmatised condition (Rawlings, Brown, Stone, & Reuber, 2017) and most individuals self-reported that they had had multiple investigations into the aetiology of their seizures. Thus, even though it is impossible to assess if individuals did have a diagnosis of NEAD, it seems likely that most individuals did. The sample had a large variety in terms of geographical location and education; however, the sample was overwhelmingly made up of white females. There is evidence to indicate that the psychological profiles of individuals with a diagnosis of NEAD are different between men and women (Myers, Trobliger, Bortnik, & Lancman, 2017). Therefore, the results of this study may not generalise beyond women, and due to the limited NEAD research within black and minority populations it is impossible to ascertain if this phenomenon generalises. It is important to note that no measure of mental health was included. However, this is not considered a limitation, simply something to consider, as this study was exploring psychological variables within a single group from a trans-diagnostic perspective of distress. Finally, all the measures included were self-reported measures, in which individuals often rated very highly. The high rating may be a limitation as the instruments might not have been sensitive enough to pick up subtle differences. Many of the included measures were short and had a one-factor structure. These measures were selected based upon the recommendation of service user groups as to limit participant burden.

Clinical Implications

The findings of this study suggest that to support people who are experiencing NEAD, decreasing levels of somatisation may help to improve their lives and reduce NEA frequency. This is consistent with previous literature which identifies that somatisation is a contributing factor in outcomes of individuals with NEAD (Reuber, House, et al., 2003). This is a hopeful perspective as many of the key components highlighted within NEAD, such as attachment history and trauma histories, cannot be changed. However, identifying how somatisation translates into the expression of NEAs may help to establish better treatment options for individuals.

Furthermore, this study provided evidence for which psychological mechanisms are best targeted to reduce somatisation, providing foundational work on the relationship between psychological inflexibility and somatisation within NEAD. Therapies which consider mindfulness, such as many third wave CBTs, may be helpful at reducing the level of somatisation that people with NEAD experience. This is consistent with literature from somatising conditions more generally (Lakhan & Schofield, 2013). Currently there is a very limited evidence-base for mindfulness-based interventions in the effective treatment and support of individuals with NEAD. This study provides preliminary evidence that levels of mindfulness contribute to a key psychological mechanism within the NEAD population. Therefore, more research is needed which investigates the effectiveness and efficacy of mindfulness-based interventions at reducing levels of somatisation, and as a result, the impact on the frequency of NEAs. Mindfulness is embedded within most third wave therapies. However, it has also effectively been integrated into CBT, which already has a strong evidence-base within NEAD (Carlson & Nicholson Perry, 2017). What is also

beneficial is that for those experiencing NEAD, there is access to many free on-line mindfulness-based interventions which have been shown to effectively increase mindfulness (van Emmerik, Berings, & Lancee, 2018).

Currently the recommended treatment for NEAD is CBT with psychoeducation, which although effective for some, leaves many without a successful remission in symptomology (Carlson & Nicholson Perry, 2017). Within NEAD it is still not clear if symptomology reduction is the best outcome. Perhaps it is time to consider outcomes in NEAD in terms of recovery and quality of life. This study provides preliminary evidence that there could be other suitable options for individuals who do not find CBT effective or who do not want to engage in a traditional CBT intervention or focus on symptomology reduction. Specifically, it would be beneficial to consider therapies which target mindfulness and acceptance, such as ACT. It is also noted that other third wave CBTs may be beneficial to support individuals with NEAD. Many third wave CBTs include elements of mindfulness and focus on acceptance of thoughts rather than attempting to change the content of thoughts (Öst, 2008).

Future Research

Clinical trials which explore the effectiveness of therapies which specifically target acceptance and include mindfulness, for individuals with NEAD are required to advance the evidence base. Of particular benefit would be a randomised control trial which compares a third wave CBT to the best-known treatment for NEAD, traditional CBT.

This study provided evidence of psychological factors which may be important within NEAD. Due to the high correlations between EA, and CF it is possible that these variables, within this population would be best looked at in a combined fashion, which

could be further explored within structural equation modelling. Furthermore, due to the interlaced nature of these constructs as well as the cyclical nature of psychological distress, it is likely that variables explored interact in a bi-directional manner. However, due to the nature of this study, directionality could not be ascertained. Therefore, future research should consider more complex modelling which would provide further understanding into such relationships.

Based on the results of the main analysis, and the post-hoc analysis, a tentative model for future structural equation modelling (SEM) is suggested, see Figure 1. However, this is a preliminary model and should be interpreted with great caution. If SEM was used it would be important to explore alternatives. Such alternatives should explore the directionality of CF, EA, and mindfulness as well as the independence of these constructs.

INSERT FIGURE 1

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Tables

Table 1

Demographic characteristics of the sample

Sample Characteristics	N (285)
Gender	
Female	247
Male	34
Non-binary gender identification	4
Age	
Minimum	18
Maximum	72
Mean (SD)	38.16 (12.03)
Ethnicity	
White	211
Black or visual minority	17
Not-disclose	57
Country of residence	
United States of America	146
United Kingdom	101
Australia	19
Canada	9
Other country	9
Not reported	1
Diagnosis procedure	
Video telemetry	210
MRI	17
In hospital not specified	30
Medical Professional	18
Not specified	10
Additional diagnosis	
Epilepsy	40
Physical health condition	32
Mental health diagnosis	227
Additional Medically Unexplained Diagnosis	26
Personality disorder	24
Employment Status	
Currently unable to work	170
Employed full time	(46 full time, 20 part time)
Student	26
Unemployed	8
Fulltime parent or carer	9
Retired	5
Not specified	1
Highest level of education	
GCSEs or equivalent	35
A levels or equivalent	85
Vocational training	56
University education	92
Left prior to GSCEs or equivalent	15

Table 2

Median and IQR of variables of interest across NEA frequency

Variable	Not having attacks (n=17)	Yearly attacks (n=28)	Monthly attacks (n=50)	Weekly attacks (n=81)	Daily attacks (n=109)	Group total (n=285)
Somatisation	12.00 (6.00)	12.00 (7.25)	13.00 (5.25)	15.00 (7.00)	15.00 (6.00)	14.00 (6.50)
Impact upon life	10 (18.00)	14.50 (17.00)	22 (16.75)	26.0 (12.50)	28.0 (12.00)	25.0 (16.50)
EA	30.0 (24.50)	31.5 (15.75)	31.00 (16.50)	33.0 (18.00)	34 (18.00)	32.0 (18.00)
CF	32.00 (19.50)	31.50 (14.00)	37.0 (16.25)	34.0 (16.50)	34.0 (15.00)	34.00 (15.00)
Mindfulness	3.60 (1.87)	3.47 (1.07)	3.47 (1.20)	3.20 (1.27)	3.27 (1.43)	3.33 (1.33)

Table 3

Correlations

Variables	1	2	3	4	5	6	7	8
1. EA	-							
2. CF	.837**	-						
3. Mindfulness	-.582**	-.570**	-					
4. Somatisation	.361**	.363**	-.509**	-				
5. Impact upon life	412**	.304**	-.305**	.400**	-			
6. Age	-.109	-.135*	.074	-.003	.064	-		
7. Sex	.059	.060	.082	-.128*	.019	.032	-	
8.NEA Frequency	.081	.011	-.104*	.191**	.353**	.-021	-.010	-

* p <.05, **p<.0005. Cohen's standard for effect size was used therefore, correlation coefficients between less than .2 were considered small, .3-.5 were identified as medium effect size, and correlation coefficients greater than .5 were identified as larger.

Table 4

First and Last models of Backwards Multiple regression with somatisation as dependent

Variable	*B*	Standard Error B	*β*	F	adj R^2	f^2
Model 1				22.076	.271	.394
Constant	18.864***	2.076				
Mindfulness	-2.175***	.326	.057			
CF	.013	.044	.131			
EA	.030	.038	-.435			
Women	1.675**	.737	.028			
Non-binary	1.943	2.120	.063			
Model 6				2.272	.263	.379
Constant	21.668***	1.101				
Women	1.328	.696	.097			
Mindfulness	-2.504***	.251	-.508			

Note: * p<.05, **p<.05 and maintains significance at Holm-Bonferroni specified alpha level, ***p<.0005

Table 5

First and Last models of Backwards Multiple regression with impact upon life as dependent variable

Variable	*B*	Standard Error B	*ß*	F	adj R^2	f^2
Model 1				18.350	.328***	.531
Constant	1.635	5.064				
EA	.329***	.082	.379			
CF	-.108	.094	-.108			
Mindfulness	.354	.742	.033			
Somatisation	.537***	.127	.244			
NEA daily	8.963***	2.222	.426			
NEA weekly	4.493***	2.379	.167			
NEA monthly	6.530	2.271	.288			
NEA yearly	-.692	2.586	-.020			
Model 4				29.078	.331***	.522
Constant	2.235**	2.002				
EA	.263***	.045	.302			
Somatisation	.492***	.116	.224			
NEA daily	9.507***	1.515	.452			
NEA weekly	7.061***	1.579	.312			
NEA monthly	4.645**	1.728	.173			

Note: * p<.05, **p<.05 and maintains significance at Holm-Bonferroni specified alpha level, ***p<.0005

Table 6

Ordinal Logistic regression with NEA frequency as the dependent variable

Variable	*B*	Standard Error B	*Exp(B)*	95% CI		Wald	χ^2
				lower	upper		
EA	.034	.0179	1.034	.999	1.071	3.563	
CF	-.045**	.0209	.956	.917	.996	4.670	
Mindfulness	.000	.1605	1.000	.730	1.369	3.560	
Somatisation	.089***	.0277	1.093	1.035	1.154	10.220	

Note: * p<.05, **p<.05 and maintains significance at Holm-Bonferroni specified alpha level, ***p<.005

Figures

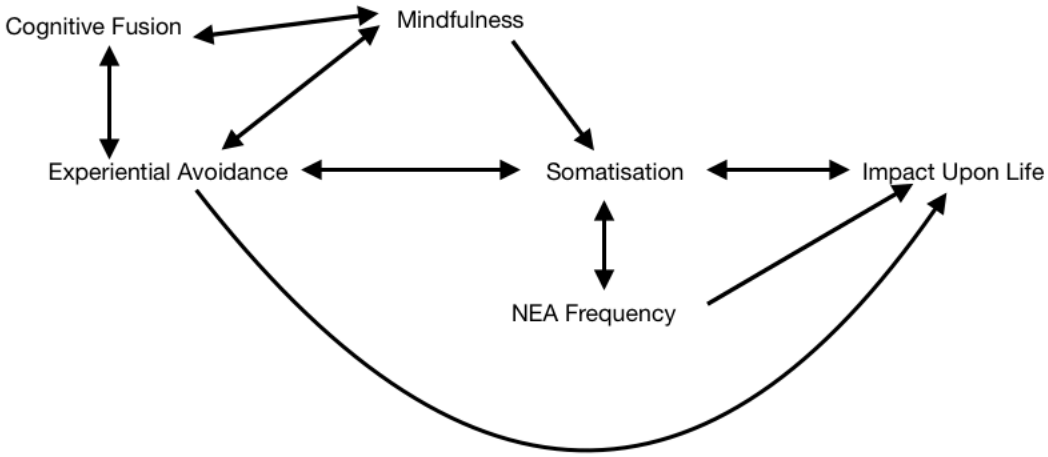


Figure 1. Proposed model for future research

Appendix 2-A

Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Mindfulness	.040	285	.200*	.990	285	.042
CF	.092	285	.000	.960	285	.000
Impact upon life	.090	285	.000	.965	285	.000
EA	.064	285	.006	.961	285	.000
Somatisation	.086	285	.000	.989	285	.025

*. This is a lower bound of the true significance.

a. Lilliefors Significance Correction

Appendix 2-B

Mann Whitney tests comparing NEAD with epilepsy to NEAD only

	Additional diagnoses (check all that apply) - Selected Choice Epilepsy	N	Mean Rank	Sum of Ranks
Mindfulnes	no	245	143.28	35104.00
	Epilepsy	40	141.28	5651.00
	Total	285		
CF	no	245	142.63	34943.50
	Epilepsy	40	145.29	5811.50
	Total	285		
EA	no	245	142.13	34821.00
	Epilepsy	40	148.35	5934.00
	Total	285		
Somatisation	no	245	144.32	35359.50
	Epilepsy	40	134.89	5395.50
	Total	285		

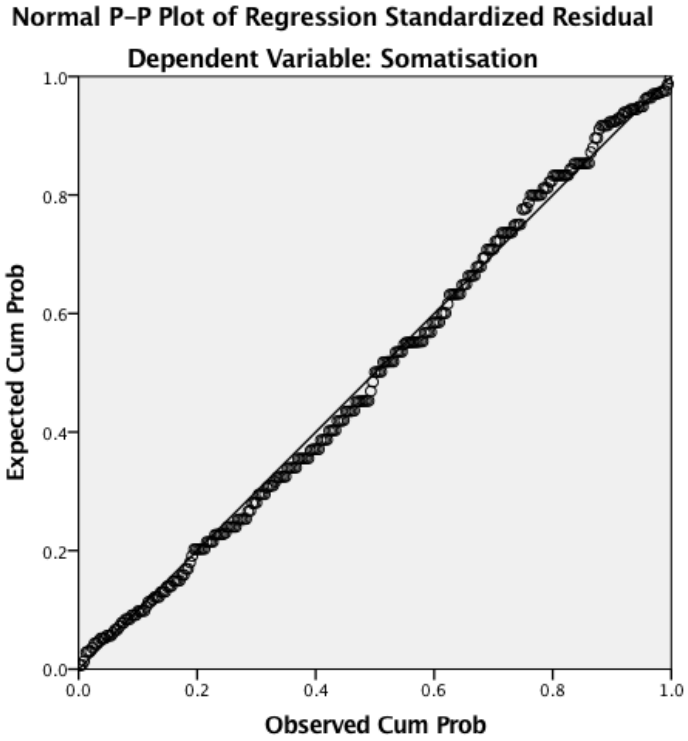
Test Statistics[a]

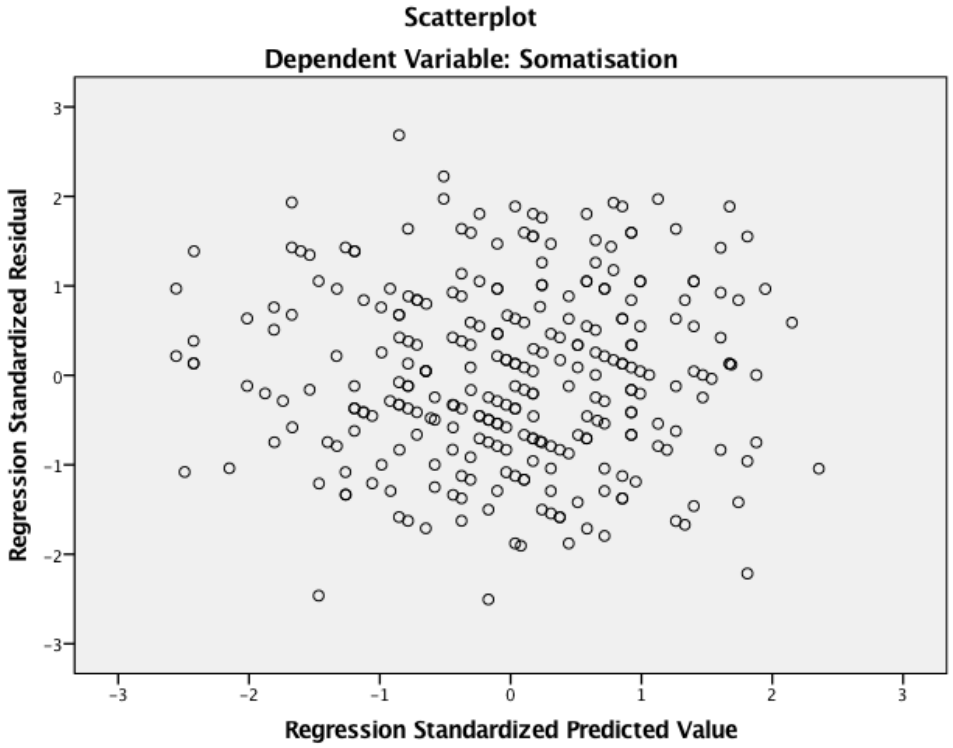
			Mindfulness	CF	EA	Somatisation
Mann-Whitney U			4831.000	4808.500	4686.000	4575.500
Wilcoxon W			5651.000	34943.500	34821.000	5395.500
Z			-.143	-.189	-.443	-.673
Asymp. Sig. (2-tailed)			.886	.850	.658	.501
Monte Carlo Sig. (2-tailed)	Sig.		.886[b]	.842[b]	.662[b]	.495[b]
	95% Confidence Interval	Lower Bound	.880	.835	.652	.485
		Upper Bound	.892	.849	.671	.504
Monte Carlo Sig. (1-tailed)	Sig.		.441[b]	.415[b]	.331[b]	.246[b]
	95% Confidence Interval	Lower Bound	.431	.405	.322	.237
		Upper Bound	.451	.425	.341	.254

a. Grouping Variable: Additional diagnoses (check all that apply) - Selected Choice Epilepsy
b. Based on 10000 sampled tables with starting seed 2000000.

Appendix 2-C

Assumptions for linear regression with somatisation as the dependent



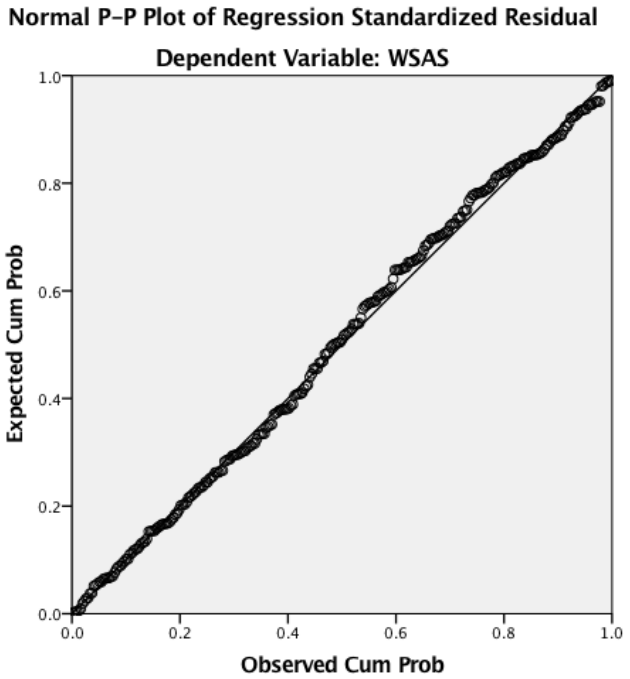


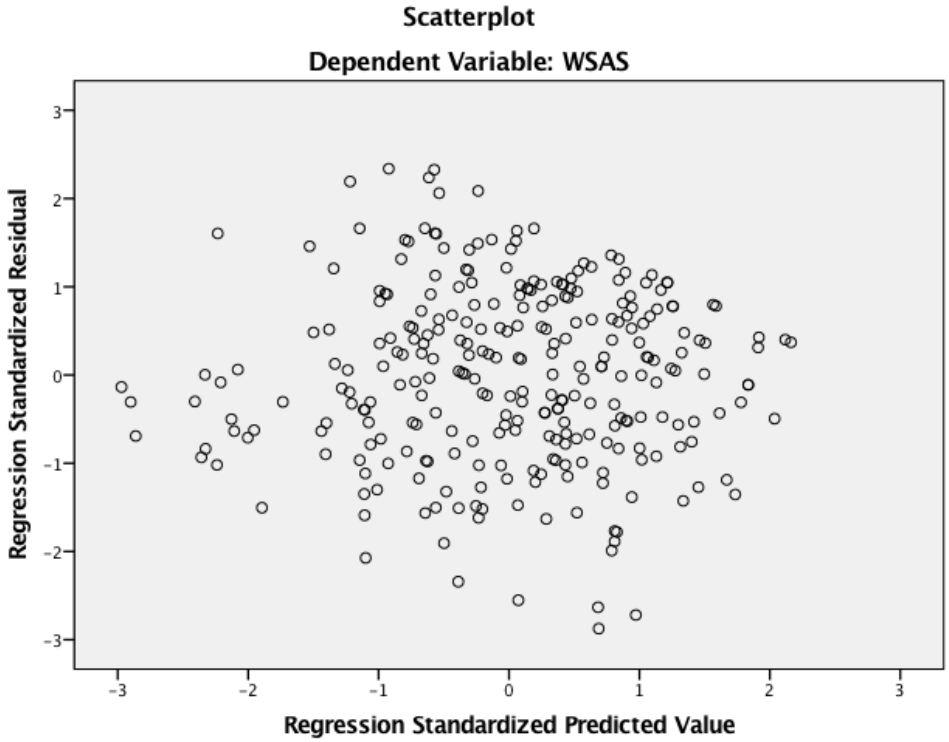
Assumptions for linear regression with somatisation as the dependent

Coefficients

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Collinearity Statistics	
		B	Std. Error	Beta			Tolerance	VIF
1	(Constant)	18.864	2.076		9.088	.000		
	Mindfulness	-2.175	.326	-.441	-6.663	.000	.587	1.705
	CF	.013	.044	.028	.293	.770	.278	3.602
	EA	.030	.038	.076	.799	.425	.283	3.529
	Women	1.675	.737	.122	2.272	.024	.885	1.129
	Non-Binary	1.943	2.120	.049	.916	.360	.894	1.119
2	(Constant)	19.113	1.890		10.113	.000		
	Mindfulness	-2.198	.316	-.446	-6.957	.000	.624	1.603
	EA	.038	.025	.097	1.516	.131	.628	1.592
	Women	1.677	.736	.122	2.278	.023	.885	1.129
	Non-Binary	2.007	2.106	.051	.953	.341	.904	1.107
3	(Constant)	19.393	1.867		10.388	.000		
	Mindfulness	-2.215	.315	-.449	-7.025	.000	.626	1.598
	EA	.038	.025	.096	1.507	.133	.628	1.592
	Women	1.461	.700	.107	2.086	.038	.978	1.023
4	(Constant)	21.668	1.101		19.672	.000		
	Mindfulness	-2.504	.251	-.508	-9.983	.000	.994	1.006
	Women	1.328	.696	.097	1.907	.058	.994	1.006

Appendix 2-D
Assumptions for linear regression with impact on life as the dependent





Assumptions for linear regression with impact on life as the dependent continued

Coefficients

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Collinearity Statistics	
		B	Std. Error	Beta			Tolerance	VIF
1	(Constant)	1.634	5.064		.323	.747		
	Mindfulness	.354	.742	.033	.477	.634	.504	1.986
	CF	-.108	.094	-.108	-1.146	.253	.265	3.772
	Somatisation	.537	.127	.244	4.217	.000	.704	1.420
	EA	.353	.081	.406	4.385	.000	.276	3.624
	People who have attacks daily	8.963	2.222	.426	4.033	.000	.212	4.722
	People who have Monthly	4.493	2.379	.167	1.889	.060	.302	3.315
	People who have attacks Weakly	6.530	2.271	.288	2.875	.004	.235	4.248
	People who have attacks yearly	-.692	2.586	-.020	-.268	.789	.417	2.398
2	(Constant)	1.268	4.867		.260	.795		
	Mindfulness	.348	.741	.032	.469	.639	.504	1.984
	CF	-.108	.094	-.109	-1.154	.250	.265	3.770
	Somatisation	.536	.127	.244	4.218	.000	.705	1.419
	EA	.353	.080	.406	4.388	.000	.276	3.623
	People who have attacks daily	9.396	1.518	.447	6.188	.000	.452	2.212
	People who have Monthly	4.927	1.740	.183	2.831	.005	.562	1.780
	People who have attacks Weakly	6.963	1.592	.307	4.375	.000	.478	2.093
3	(Constant)	3.313	2.166		1.530	.127		
	CF	-.118	.091	-.119	-1.295	.196	.279	3.578
	Somatisation	.513	.117	.234	4.370	.000	.821	1.217
	EA	.347	.079	.399	4.376	.000	.283	3.529
	People who have attacks daily	9.378	1.516	.446	6.187	.000	.452	2.211
	People who have Monthly	4.904	1.737	.183	2.823	.005	.562	1.778
	People who have attacks Weakly	6.894	1.583	.304	4.356	.000	.482	2.076
4	(Constant)	2.235	2.002		1.117	.265		
	Somatisation	.492	.116	.224	4.223	.000	.839	1.192
	EA	.263	.045	.302	5.776	.000	.863	1.159
	People who have attacks daily	9.507	1.514	.452	6.278	.000	.454	2.201
	People who have Monthly	4.645	1.728	.173	2.689	.008	.570	1.755
	People who have attacks Weakly	7.061	1.579	.312	4.471	.000	.485	2.062

Appendix 2-E

Assumptions for ordinal regression with NEA frequency as the dependent

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Collinearity Statistics	
		B	Std. Error	Beta			Tolerance	VIF
1	(Constant)	2.446	.665		3.677	.000		
	EA	-.037	.104	-.029	-.356	.722	.510	1.962
	CF	-.027	.013	-.232	-2.126	.034	.281	3.563
	Mindfulness	.021	.011	.201	1.861	.064	.286	3.494
	Somatisation	.054	.018	.209	3.079	.002	.730	1.370

a. Dependent Variable: NEA frequency daily, weekly, monthly, yearly, none

Test of Parallel Lines[a]

Model	-2 Log Likelihood	Chi-Square	df	Sig.
Null Hypothesis	795.790			
General	776.555[b]	19.235[c]	12	.083

The null hypothesis states that the location parameters (slope coefficients) are the same across response categories.

a. Link function: Logit.

b. The log-likelihood value cannot be further increased after maximum number of step-halving.

c. The Chi-Square statistic is computed based on the log-likelihood value of the last iteration of the general model. Validity of the test is uncertain.

Appendix 2-F

Author guidelines for target journal Seizure

For author guidelines see Appendix 1-C.

3. Critical Appraisal

Critical Appraisal of the Thesis Psychological Inflexibility within Non-Epileptic Attack Disorder

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May 2018

Critical appraisal of the thesis psychological inflexibility within non-epileptic attack disorder

Non-epileptic attack disorder (NEAD) is the term provided to individuals who experience medically unexplained involuntary sudden attacks which look like epileptic seizures. Falling between the care of psychologists, neuro-psychologists, psychiatrists, and neurologists (LaFrance, Rusch, & Machan, 2008), individuals with NEAD often feel stigmatised and left without adequate support following their diagnosis (Robson, Myers, Pretorius, Lian, & Reuber, 2018). The diagnosis of NEAD can be confusing for many individuals (Carton, Thompson, & Duncan, 2003; Thompson, Isaac, Rowse, Tooth, & Reuber, 2009). Prior to receiving a diagnosis of NEAD people are often misdiagnosed as having epilepsy (Bodde, Brooks, Baker, Boon, Hendriksen, & Aldenkamp, 2009; Reuber, Fernandez, Bauer, Helmstaedter, & Elger, 2002). Unlike epilepsy there is not a clear treatment plan for individuals who receive a diagnosis of NEAD (Bodde, Brooks, et al., 2009). Interventions to support people with a diagnosis of NEAD remain unclear, with professionals often feeling unequipped to support individuals (Rawlings & Reuber, 2018). This is often due to medical professionals' view that they are unable to support individuals with NEAD (Rawlings & Reuber, 2018). Currently there is limited evidence as to what may be the best treatment for individuals with NEAD (Carlson & Nicholson Perry, 2017). This results in people being referred to various professionals before they receive the appropriate support. The label alone hints at these difficulties. Stone et al. (2003) criticise the lack of clarity as it is a non-diagnosis, stating to individuals that they have a diagnosis of not having something else. In spite of this, it is difficult to identify a name which would be more appropriate. Brigo et al. (2015) recommend the term psychogenic non-epileptic

seizures (PNES). However, labels which include the prefix of 'psycho' have been viewed as stigmatising by people who receive the diagnosis (Stone et al., 2003).

NEAD is still a poorly understood phenomenon and there is debate as to how it can best be explained and understood. Much of the conceptualisation of this thesis was based on the Brown and Reuber (2016) theoretical integrative cognitive model of NEAD. Brown and Reuber's (2016) model suggests that individuals will experience stressors which contribute to the development of a "seizure scaffold" and that a deficit in inhibitory processes triggers the NEA. This seizure scaffold is activated when individuals experience internal or external triggers, such as trauma memories, hypo/hyper arousal, and daily stressors which lead the individual to identify a seizure risk (Brown & Reuber, 2016). Once a trigger has been identified, individuals then anticipate a seizure which in turn activates the seizure scaffold. Following the activation of seizure scaffold, it is a deficit in inhibitory processing which causes the NEA (the physical manifestation of the seizure scaffold).

Considering what is known about NEAD, two key questions were identified:

1) What factors underlie NEAD?

2) Are these factors accounted for by psychological theory which would help develop or utilise an already existing suitable treatment model?

The concept of psychological inflexibility has been found to be important to a wide variety of expressions of psychological distress (Hayes, 2004). Psychological inflexibility occurs when individuals become bound up with their thoughts, a process referred to as cognitive fusion (CF). This fusion with thoughts, results in individuals experiencing thoughts as concrete events and absolute truths, which therefore must be responded to as

such. Distressing thoughts, physical sensations, and emotions can thus be experienced as highly threatening (Fletcher & Hayes, 2005; Hayes, 2004). Individuals may then try to actively avoid such experiences, a process known as experiential avoidance (EA). Individuals are then not able to live mindfully, as they are focusing on internal experiences in an attempt to prevent and control them rather than accepting them.

Acceptance and commitment therapy (ACT) views psychological inflexibility as the core component of psychological distress and specifically targets elements such as EA with the aim of reducing psychological inflexibility. The main outcome of ACT is not symptom reduction or amelioration but instead an increase in psychological flexibility. This is achieved through increasing acceptance of private experiences and living in the moment, in a way which is aligned with personal values and beliefs. These goals are achieved through increasing levels of mindfulness and acceptance. Furthermore, there is empirical evidence which indicates that ACT is effective in both medically unexplained presentations and presentations of individuals with epilepsy (see Cope, Poole, & Agrawal, 2017 for full review). Considering the theoretical underpinnings of ACT, it seems highly possible that core components of the ACT model may be theoretically linked with the NEAD population. This thesis aimed to explore variables within the NEAD population, which are considered key components of psychological inflexibility

To understand how variables of psychological inflexibility may theoretically be important within NEAD, variables of psychological inflexibility were considered in conjunction with Brown and Reuber (2016). Three key components of psychological inflexibility, were identified, as relevant considering Brown and Reuber (2016): EA, CF, and mindfulness. EA is an active process and one must therefore scan, select, and monitor

thoughts to ensure the dangerous thoughts do not occur. Therefore, engaging in EA can paradoxically intensify and strengthen unwanted thoughts (Hayes, 2004), increasing individuals' susceptibility to overwhelming emotions, promoting hyper/hypo arousal, thus potentially initiating the process of triggering an NEA according to Brown and Reuber's (2016) model. CF may then be implicated in the translation of the 'seizure scaffold', the cognitive representation of the NEA, into a physical NEA as individuals with high levels of CF are more bound up with their cognitions and are therefore likely to be highly entangled with the cognitive representation of the NEA. Central to mindfulness is the ability to pay attention and choose how to respond to thoughts (Shapiro, Carlson, Astin, & Freedman, 2006). Increasing levels of mindfulness has been demonstrated to increase individuals' ability to freely choose how they attend and respond to thoughts (Harris, 2009). Brown and Reuber (2016) suggest that individuals with NEAD have a deficit in inhibitory process and it is a deficit in inhibitory processing which gives the individual no option but to succumb to the overwhelming urge of the seizure scaffold. Therefore, it was theorised at the outset of this thesis that the lack of being able to choose how to respond to thoughts may result in increased, yet unsuccessful, attempts to prevent the thoughts of an NEA.

Outcome Variables Within NEAD

A key issue for NEAD research which was reflected in the empirical paper relates to identifying the most appropriate outcomes. NEA remission has often been used as a measure of outcome. The rationale for this outcome is likely bound up with where the research has come from. The predominant research within NEAD has come from a medical perspective, specifically one of neurology. The outcomes appear to be borrowed from epilepsy, whereby the goals of treatment are to reduce the amount of seizures.

However, where NEAD is psychological in nature, outcome variables which are based more on psychological outcomes and quality of life should be considered. That is not to say that NEA frequency should be discounted as an outcome measure, simply that it needs to be considered in conjunction with additional outcomes (Bodde, Brooks, et al., 2009). Therefore, despite its limitations, it was included as one of the outcome variables within this thesis. NEA frequency was defined by categories of having NEAs: yearly, weekly, monthly, daily, or not currently having NEAs. Impact upon life was selected as an outcome as it relates to how much an individual can enjoy and access multiple elements of their life. This measure was selected over quality of life as it takes a measure of the direct way NEAD is preventing someone from doing things in their life. Furthermore, this measure is frequently used within the United Kingdom within mental health services. Some confidence in using this as an outcome may be derived from the close relationship it exhibited with NEA frequency in the empirical paper. Finally, somatisation was chosen as it has been identified as being linked with outcome and quality of life for individuals with NEAD (Wolf et al., 2015). Understanding more about the process of somatisation with NEAD was therefore thought to be beneficial.

Findings of This Thesis

The systematic literature review highlighted that people affected by NEAD tend to be high on levels of avoidance. However, currently there is not enough research to indicate if it is in excess of what has been found within populations of individuals with other mental health difficulties. In terms of clinical relevance, that may not be important as individuals with NEAD often experience multiple difficulties (D'Alessio et al., 2006). Therefore, when considering psychological interventions, it would be beneficial to consider the role

avoidance may have in an individuals' distress. The empirical component of this thesis identified that somatisation is correlated with EA, CF, mindfulness, and NEA frequency. However, when EA, CF and mindfulness were considered in a model together, only mindfulness contributed uniquely to somatisation. A post-hoc analysis indicated that the relationship between EA and somatization, and CF and somatisation were fully mediated by mindfulness. The second question explored how much these variables, as well as NEA frequency predicted the perceived impact upon life. CF, EA, somatisation, and NEA frequency were all found to be highly correlated with impact upon life. Higher levels of CF, EA, and lower levels of mindfulness as well as more NEAs were associated with having a greater impact upon life. When considered together, all variables except for CF and mindfulness were found to uniquely predict impact upon life. Somatisation and NEA frequency were found to contribute the largest portion of variance of the impact upon life variable. The final analysis explored NEA frequency and found that somatisation increased the odds of having a greater number of NEAs. NEA frequency, mindfulness and somatisation were all found to significantly correlate, however, when explored through ordinal regression, neither mindfulness nor EA were found to increase the odds of having an NEA. It was hypothesised that mindfulness would directly contribute to NEA frequency. However, this was not found. What is interesting is that NEA frequency was related to somatisation and somatisation was predicted by mindfulness. Contrary to the hypothesis and the consideration of Brown and Reuber (2016) mindfulness was not directly implicated within NEA frequency. However, this finding does not necessarily indicate that inhibitory control, as suggested by Brown and Reuber (2016) is not important in the translation of the thought of an NEA into its physical manifestation. Mindfulness was

strongly correlated with somatisation and was found to uniquely predict somatisation. Somatisation in turn was highly important within NEA frequency, with mindfulness and somatisation being highly related and strongly correlated. Interestingly, CF was not correlated with NEA frequency but was found to statistically significantly reduce the odds of experiencing higher frequency NEAs. This is possibly to do with the relationship of CF to NEA frequency, as this was not linear whereas EA, impact upon life, mindfulness, and somatisation all followed a general trend of increasing with NEA frequency. Linearity is not an assumption of ordinal regression yet it may impact the clinical relevance of these results. CF was found to be highest in the monthly group and the not having attacks group was found to have lower levels of CF than the group of individuals experiencing yearly attacks. Therefore, there was heavy weighting on higher levels of CF in the lower frequency NEA groups when considered within the regression. It is also interesting that CF was not correlated with NEA frequency in a univariate capacity. This indicates that there were possible suppressor effects occurring, highlighting the complex relationship between the variables explored. Although interesting findings, at this stage it is impossible to say if this is a true result or if this is due to chance, and the significant finding of CF is in fact a type one error.

It was also found that within the NEAD population CF and EA were highly correlated. This correlation did not violate the assumption of multicollinearity. However, it does pose the question: should these two concepts be considered separately? Gillanders et al. (2014), identifies that there is an unclear relationship between EA and CF. Suggesting that CF and EA may be interdependent and that although the measures are tapping into different constructs it may be that you cannot have one without the other.

Gillanders et al. (2014) identifies that it is also possible that different populations utilise EA and CF together in different ways and in some populations, they may indeed be the same construct. However, at this point in time, there is not enough research in the area to identify if this is the case. It is interesting that within this thesis EA and CF were highly correlated $r=.837$, $p<.0005$. However, when considering NEA frequency, the data did not follow the same path, suggesting that CF and EA may yet be distinctive concepts within NEAD. Furthermore, both CF and EA uniquely contributed to the variance observed within mindfulness as measured by the MAAS.

Measurement Difficulties

Identifying the most appropriate measures within the area of psychological inflexibility is, at this point in time, still unclear. Across the literature there is limited consistency as to how to define the variables of mindfulness, CF, and EF. Construct validity of psychological inflexibility, and the individual variables of which it is composed, has been questioned (Wolgast, 2014). Mindfulness is defined differently throughout the literature, as for the purpose of this thesis, a measure of dispositional mindfulness was selected, this measure is highly correlated with the operationalisation of mindfulness within ACT. However, Baer et al. (2008) suggest that a one factor measure of mindfulness may over-simplify the construct and that a multi-factor measure is more accurate at identifying components of mindfulness. Furthermore, it is worth considering the questionnaire used to measure EA in this thesis. Although the Acceptance and Action Questionnaire-two (Bond et al., 2011) is a highly utilised measure, it has been criticised for its construct validity. Suggesting that it actually measures multiple components of psychological inflexibility and anxiety more generally (Wolgast, 2014). Future research into the area should focus on

additional measures of EA and mindfulness. It is also recommended that future research, which includes variables of psychological inflexibility, include confirmatory factor analysis. This would help to identify the relationships between these constructs.

Conclusions and Limitations

There are several limitations to this thesis in regards to the generalisability of the findings. Online recruitment draws into question the reliability of NEAD diagnosis and representativeness of the sample. However, as mentioned in the empirical paper, this is not thought to be a significant concern. The systematic literature review highlights the importance of EA within NEAD, however due to the nature and methodology of the evidence base, it is not possible to identify the specific elements of EA that may be important. The construct of EA was not consistent across papers and is very broadly defined. A clear operationalisation of EA in future research would be beneficial.

Although there are limitations it is believed that this thesis contributes to the body of knowledge on NEAD by providing an empirical understanding of how psychological variables may be related to NEAD. This study was exploratory in nature and utilised a cross-sectional design therefore causality could not be identified. To the best of this researcher's knowledge this is the first empirical study which has examined multiple components of psychological inflexibility within NEAD. This provided novel insights into how NEAD may be maintained from a model which is not based upon psychiatric constructs. Mindfulness has not previously been explored within NEAD. This thesis provided evidence that mindfulness is of relevance within NEAD and although highly correlated with EA and CF is not simply an inverse of these processes. However, much more research is needed into this area to understand how such concepts may work within

NEAD and how they may relate to the maintenance of NEAD. The data do help provide direction in this regard and potential development of more effective psychological interventions.

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4. Ethical Proposal

Applicant: Tasha Cullingham
Supervisor: Bill Sellwood
Department: Health Research
FHMREC Reference: FHMREC16129

21 August 2017

Dear Tasha

Re: Examining Psychological Principles in Non-Epileptic Attack Disorder from an Acceptance and Commitment Point of View

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 592838
Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

Dr Diane Hopkins
Research Integrity and Governance Officer, Secretary to FHMREC.

Faculty of Health and Medicine Research Ethics Committee Form

Health & Medicine | Lancaster University

Faculty of Health and Medicine Research Ethics Committee (FHMREC)
Lancaster University

Application for Ethical Approval for Research [guidance1]

for additional advice on completing this form, hover cursor over 'guidance'.

Guidance on completing this form is also available as a word document

Title of Project [guidance 2]:
Examining Psychological Principles in Non-Epileptic Attack Disorder from an Acceptance and Commitment Point of View

Name of applicant/researcher: Natasha Cullingham

ACP ID number (if applicable)*: **Funding source (if applicable)**

Grant code (if applicable):

***If your project has *not* been costed on ACP, you will also need to complete the Governance Checklist [link].**

Type of study

☐ Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one, *two* and four of this form**

☒ Includes *direct* involvement by human subjects. **Complete sections one, *three* and four of this form**

SECTION ONE

1. Appointment/position held by applicant and Division within FHM Trainee Clinical Psychologist

2. Contact information for applicant:
E-mail: t.cullingham@lancaster.ac.uk **Telephone:** 07746340840 (please give a number on which you can be contacted at short notice)

Address: 41 White Moss Ave, Manchester M21 0XS

3. **Names and appointments of all members of the research team (including degree where applicable)**

Prof. Bill Sellwood, Programme Director, Lancaster Doctorate of Clinical Psychology
Dr. Fiona Eccles, Lecturer, Lancaster University
Dr. Antonia Kirkby, Consultant Neuropsychologist, Salford Royal Hospital

May 2017

3. If this is a student project, please indicate what type of project by marking the relevant box/deleting as appropriate: (please note that UG and taught masters projects should complete **FHMREC form UG-tPG**, following the procedures set out on the FHMREC website

PG Diploma ☐ Masters by research ☐ PhD Thesis ☐ PhD Pall. Care ☐

PhD Pub. Health ☐ PhD Org. Health & Well Being ☐ PhD Mental Health ☐ MD ☐

DClinPsy SRP ☐ [if SRP Service Evaluation, please also indicate here: ☐] DClinPsy Thesis ☒

4. Project supervisor(s), if different from applicant: Prof Bill Sellwood

5. **Appointment held by supervisor(s) and institution(s) where based (if applicable):** Programme Director Lancaster Doctorate of Clinical Psychology

SECTION TWO

Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants

1. Anticipated project dates (month and year[guidance 3])
Start date: End date:

2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language[guidance 4]):

Data Management

For additional guidance on data management, please go to Research Data Management webpage, or email the RDM support email: rdm@lancaster.ac.uk

3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.

4a. How will any data or records be obtained?

4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms' n o
4c. If yes, where relevant has permission / agreement been secured from the website moderator? n o
4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users? n o

4e. If no, please give your reasons

5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc[guidance5])? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with the Data Protection Act 1998.
See attached data management plan

6a. Is the secondary data you will be using in the public domain? n o
6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.

Please answer the following question *only* if you have not completed a Data Management Plan for an external funder

7a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE[guidance6]?

7b. Are there any restrictions on sharing your data[guidance7]?

8. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications?

yes

b. How will the confidentiality and anonymity of participants who provided the original data be maintained?

9. What are the plans for dissemination of findings from the research[guidance 8]?

10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

SECTION THREE

Complete this section if your project includes *direct* involvement by human subjects

1. Summary of research protocol in lay terms (indicative maximum length 150 words[guidance 9]):

Non-epileptic Attack Disorder (NEAD) is a medically unexplained phenomenon whereby people experience involuntary movements observably similar to that of an epileptic seizure. However, upon investigation, there is no identifiable organic cause. We want to look at if being bound up (cognitive fusion) with your thoughts as well as pushing thoughts away (experiential avoidance) contributes to people experiencing physical sensations that cannot be explained by our current medical knowledge. We also want to look at the role mindfulness plays in this relationship. I.e. does mindfulness mitigate the impact that cognitive fusion and experiential avoidance have on somatisation for people with a diagnosis of NEAD? To do this we are going to ask individuals with a diagnosis of NEAD to volunteer to complete questionnaires on-line about: experiential avoidance, cognitive fusion, mindfulness, somatization and emotional regulation.

2. **Anticipated project dates (month and year only[guidance 10])**

Start date: July 2017 End dateAugust 2018

Data Collection and Management

For additional guidance on data management, please go to Research Data Management *webpage, or email the RDM support email:* rdm@lancaster.ac.uk

3. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender[guidance 11]):

Participants will be individuals with a diagnosis of NEAD. The minimum age will be 18 years old, the minimum number of participants is 107 based on an a prior power calculation, all genders are welcome to participate. Although viewed as unlikely to obtain such a number the maximum number of participants will be 1000. Participants must have a diagnosis of NEAD to be included in the study.

4. How will participants be recruited and from where? Be as specific as possible[guidance 12]. Ensure that you provide the *full versions* of all recruitment materials you intend to use with this application (eg adverts, flyers, posters).

10. What discomfort (including psychological eg distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks [guidance 19]. State the timescales within which participants may withdraw from the study, noting your reasons.[guidance 20]

There are minimal risks anticipated with participating in this study. Due to the nature of the questions being asked and the questionnaires selected it is possible that difficult feelings may arise during the completion of this study. If individuals do become distressed it will be recommended, both in the participant information sheet which will appear on screen prior to obtaining consent and in the debrief sheet following the study, that they contact their GP if distressing feelings arise. Contact information for Mind and Rethink Mental illness will also be provided.

It is a project involving straightforward issues which can be identified and managed routinely in accordance with standard research practice and existing guidelines. For example, the provision of contact details for mental health support and individuals being able to withdraw at any point of time whilst completing the questionnaires. The lead researcher is a current trainee in Clinical Psychology, supervised by three experienced clinical researchers in research with people who may be experiencing distressing emotions, and specifically trained to conduct quantitative research. Therefore, when designing the study the researcher and supervisors considered the impact of the questions on individuals and questionnaires with limited time and emotional burden were selected. The data generated by this research will be anonymous and maintained according to the Good Clinical Practice Guidelines by the NIHR, and the Declaration of Helsinki published by the World Medical Association.

As this is an on-line study individuals will be provided with an option saying they do not want their data to be used. Participation is voluntary and participants are able to stop completing the forms as any point in time.

11. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take[guidance 21]).

There are no identified risk to the researcher.

12. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study[guidance 22].

There are no direct benefits to participants for taking part.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants[guidance 23]: None to be provided.

14. Confidentiality and Anonymity
a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications?
yes
b. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality[guidance 24].

No individual data will be presented nor will any identifiers be included within any write-up of the study. All data will be anonymised.

15. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research[guidance 25].

NEADuk and FNDhope have been contacted to gain service user input. Clinicians working in the area have been involved in the planning of the project to identify areas which will be beneficial to clinicians and the population.

16. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis[guidance 26].

The results of this research study will be written up as a Doctorate of Clinical Psychology thesis. Following the submission of the thesis this project will seek publication in Epilepsy & Behaviour which has an impact factor of 2.332.

A summary flyer will be created which will be shared on twitter and with the service user groups which have been involved.

The supervisory team will have access to the dataset as needed.

17. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study[guidance 27]? Are there any matters about which you wish to seek guidance from the FHMREC?
No additional concerns have been identified at this point in time.

Research Protocol

Research Team

Lead Researcher: Tasha Cullingham, Trainee Clinical Psychologist at Lancaster University
Field Supervisor: Dr. Antonia Kirkby, Consultant Clinical Neuropsychologist, Salford Royal
Internal Academic supervisor: Professor Bill Sellwood, Programme Director, Doctorate in Clinical Psychology, Lancaster university
Additional Internal Academic Supervisor: Dr. Fiona Eccles, Lecturer, Doctorate in Clinical Psychology, Lancaster University

Study Rationale

Non-Epileptic Attack Disorder

Non-Epileptic Attack Disorder (NEAD) is a medically unexplained phenomenon whereby people experience involuntary movements observably similar to that of an epileptic seizure. However, unlike with epilepsy, upon investigation there is no evidence of neurological epileptiform discharges (Brown & Reuber, 2016b; Francis & Baker, 1999). Non-epileptic attacks (NEAs) are believed to be caused and mediated by psychological factors (Bodde et al., 2009) as opposed to organic physiopathology. Of individuals referred to secondary epilepsy clinics 5-40% will receive a diagnosis of NEAD (Robbins, Larimer, Bourgeois, & Lowenstein, 2016). Within the general population NEAD has a prevalence of 2-33 per every 100,000 People (Benbadis & Hauser, 2000).

It has been suggested that there are different sub-categorisations of NEAD and that individuals who belong to these subgroupings may have different aetiologies with different psychological diagnoses (Brown et al., 2013; Tallentire, 2015). However, Brown and Reuber (2016b) suggest that although there may be different psychological profiles within the NEAD population, it is not necessarily beneficial to investigate NEAD based on psychological diagnosis as there are probably common processes that contribute to NEAD independent of such categorisations. For example, It has been demonstrated that somatisation distinguishes individuals with NEAD from individuals with epilepsy more reliably than psychiatric diagnosis or psychopathological conceptualisations of distress such as anxiety or depression (Reuber, House, et al., 2003). Brown and Reuber (2016) suggest a theoretical integrative cognitive model which is common to all individuals who experience NEAD, where stressors contribute to the development of a "seizure scaffold" and a deficit in inhibitory processes triggers the NEA. This seizure scaffold is activated when individuals experience internal or external triggers, such as trauma memories, hypo/hyper arousal, and daily stressors which lead the individual to identify a seizure risk (Brown & Reuber, 2016b). B suggest that individuals will have a heightened threat-based attentional focus on physical symptoms, which makes the individual more likely to identify indications of a seizure. Once a trigger has been identified, individuals then anticipate a seizure which in turn activates the seizure scaffold. Following the activation of seizure scaffold, it is a

deficit in inhibitory processing which causes the NEA (the physical manifestation of the seizure scaffold).

Somatisation and NEAD

Somatisation is the physical expression of psychological distress whereby no medical explanation can be found (Burton, 2003). Somatisation scores have been found to discriminate best between epilepsy and NEAD groups and somatisation scores have been found to be most linked with outcome and measures of NEAD severity (Reuber, House, et al., 2003). Reuber, House, et al. (2003) suggest that somatisation rather than disassociation, as previously thought by many researchers, is an independent factor associated with NEAD, across the whole population of individuals experiencing NEAD. Owczarek (2003) identified that individuals with NEAD consistently presented with higher leaves of somatisation than individuals with epilepsy across four of five domains of somatisation. Individuals with NEAD significantly focused on bodily sensations, more than those with epilepsy, as well as attributed physical sensations more readily to illness, and experienced more negative physical sensations, particularly neurological difficulties, than those with epilepsy. The only area in which no significant difference was observed by Owczarek (2003) was that of concerns with state of health and physical appearance. Within the NEAD population high levels of somatisation has been linked with poorer outcomes, such as more hospitalisations and dependence (Reuber et al., 2005). Although somatisation is not exclusive to NEAD, as high rates of somatisation have been found in other medically unexplained phenomena (Brown et al., 2013; Burton, 2003), it does appear that somatisation is an important psychological process linked with NEAD (Owczarek, 2003; Reuber, House, et al., 2003).

Treatment and Support for NEAD

The recommended intervention for individuals with NEAD is psychotherapy (Smith, 2014). However, there is limited empirical evidence exploring which types of therapy are best suited to support individuals with NEAD (Bodde et al., 2009; Smith, 2014). The majority of research exploring therapeutic outcome and NEAD has focused on traditional Cognitive Behavioural Therapy (CBT). Throughout the literature CBT is cited as an effective therapy for many difficulties, however CBT is not effective for all individuals (LaFrance et al., 2014; Lappalainen et al., 2007; Morley et al., 2008). Third wave therapies such as Acceptance and Commitment Therapy have been identified as possible alternatives in supporting individuals experience psychological distress (Lappalainen et al., 2007; Morley et al., 2008). However, there is currently little research exploring such therapies within the NEAD population.

Furthermore, CBT models are often based upon diagnostic constructs such as depression or anxiety (Lappalainen et al., 2007). However, individuals with NEAD cannot easily be defined by a singular psychopathological category. Therefore, it can be hard for clinicians to access the evidence-base for therapies. Although CBT has been found to be effective at reducing seizure frequency (Smith, 2014), Reuber et al. (2005) identified that seizure remission may not be an accurate measure of outcome for individuals with NEAD, finding that seizure remission is not a clear indication of quality of life and productivity. Although seizure remission is linked with quality of life for individuals with epilepsy, seizures reduction alone does equate to improvements for individuals with NEAD. Therefore, it is difficult evaluate the current literature on the effectiveness of therapeutic outcome. Underlying psychological mechanisms which contribute to NEAD need to be included as outcome measures to truly identify

effectiveness of treatment. However, to do this, more insight is needed into psychological mechanisms which may be relevant in the maintenance of NEAD. In addition, the enhancement of depends upon understanding psychological mechanisms which contribute to NEAD.

Acceptance and Commitment Therapy and NEAD

Acceptance and Commitment Therapy (ACT) focuses on increasing psychological flexibility by changing an individual's relationship with their thoughts using mindfulness, acceptance, and cognitive techniques. ACT is effective in moderating the impact of both epilepsy and medically unexplained symptoms on individuals' quality of life (Lundgren, Dahl, Yardi, & Melin, 2008; Veehof, Oskam, Schreurs, & Bohlmeijer, 2011). ACT is based on Relational Frame Theory (Hayes, 2004) which suggests that language creates a mechanism for neural entanglement (cognitive fusion) which is central to psychopathology (Fletcher & Hayes, 2005). Despite the positive outcomes of ACT with other medically unexplained conditions, there is currently little research linking ACT principles with NEAD. Theoretically the mechanisms targeting cognitive fusion, experiential avoidance and not being present or 'mindlessness' (Fletcher & Hayes, 2005; Hayes, 2004) lend themselves well to Brown and Reuber's (2016) integrative cognitive model of NEAD. However further research is needed to validate this assertion. Cognitive fusion is the inability to distinguish thoughts from actions and feelings (Fletcher & Hayes, 2005; Hayes, 2004). This may link with Brown and Reuber's (2016) concept of a deficit in inhibitory process, and the seizure scaffold being reinforced each time a seizure is experienced. When in a state of cognitive fusion, individuals may engage in experiential avoidance such as thought and emotion suppression and control; and behavioural avoidance to try and avoid highly distressing thoughts, feelings and situations (Fletcher & Hayes, 2005; Hayes, 2004). Experiential avoidance can be either voluntarily or involuntary and individuals are often not aware that they are engaging in experiential avoidance (Roberts & Reuber, 2014). Dimaro et al. (2014) linked somatisation and experiential avoidance with individuals who had a diagnosis of NEAD. Individuals with NEAD often have more avoidant coping styles and utilise more thought suppression styles (Bakvis, Spinhoven, Zitman, & Roelofs, 2011). By trying to avoid thoughts of a seizure individuals may inadvertently be shaping the "seizure scaffold" as avoidance can actually intensify and strength thoughts and emotions (Hayes, 2004). The final key area of investigation is a lack of mindfulness referred to by Hayes (2004) as 'mindlessness'. Mindfulness as defined by Harris (2009, p. 8) is " paying attention with flexibility, openness and curiosity". Brown and Reuber (2016) suggest that attentional training techniques, such as mindfulness, may be helpful to prevent the activation of the seizure scaffold. Mindfulness has been demonstrated to make individuals feel more able to freely choose how they attend and respond to thoughts (Harris, 2009).

Research Aims and Questions

The current study aims to explore the impact of cognitive fusion, experiential avoidance, and mindlessness on the presence of somatisation in NEAD. What is the relationship between the ACT principles of cognitive fusion, experiential avoidance, and mindfulness with somatisation in individuals with a diagnosis of NEAD? What is the impact of Somatisation on productivity for individuals with NEAD?

Methods

Design

An online single group quantitative observational design will be utilised. Two multiple regression models will be completed to explore the research questions. For the first model the criterion variable will be somatisation with predictor variables of cognitive fusion, experimental avoidance, emotional regulation, mindfulness will be loaded into the model to explore the possibility of being a moderator variable. The second regression will be completed with the Work and Social Adjustment Scale as the criterion variable.

Participants

A minimum of 107 participants with a diagnosis of NEAD will be recruited. Sample size was determined by an a priori power analysis conducted using Gpower*. Considering an alpha value of p=.025 and $\beta = 0.15$ a sample size of 107 participants will identify a medium effect size (F=.15). Alpha value was corrected using Bonferroni correction to permit two regression models to be completed without inflating the chance of committing a type one error.

Participant Recruitment

Participants will be recruited via social media such as Twitter and Facebook as well as through support groups and charities supporting individuals with NEAD.

Materials

Physical Health Questionnaire -15 (Interian, Allen, Gara, Escobar, & Díaz-Martínez; Spitzer et al., 1999) Measures somatisation and physical symptoms. This is a questionnaire which has been utilised in numerous populations and has an internal consistency of .79. Kroenke et al. (2010) completed a systematic literature review and found the PHQ to be a reliable measure of somatisation.

Difficulties in Emotion Regulation Scale Short Form (Gratz & Gunderson, 2006; Kaufman et al.). The Difficulties in Emotion Regulation Scale has been used in numerous publications concerning emotional regulation and has been used previously in both research exploring personality disorder and NEAD populations. The short form has similar psychometric properties to the long form and has been identified as a valid measurement (Kaufman et al., 2016). This scale is being used as there has been evidence to suggest that within NEAD there are subgroups which can be distinguished by deficits in emotional regulation vs. healthy emotional regulation. This measure is being included so that analyses can be done based on the different subgroups if appropriate.

Acceptance and Action-II scale (Bond et al., 2011). Measures the construct of experiential avoidance and acceptance. Has a mean alpha coefficient of .84 and a 12-month test- retest reliability of .79.

Mindful Attention Awareness Scale (Brown & Ryan, 2003). The MAAS has been found to be a reliable and useful measure of mindfulness. The MAAS has high internal consistency (Cronbach's alpha= .89).

Cognitive Fusion Scale (Gillanders et al., 2014). The CFS is a measure of the construct of cognitive fusion. This scale has been shown to differentiate significantly between distressed and non-distressed samples. This scale has also been found to have a good internal consistency with a Cronbach's alpha of .88 in a mixed mental health sample and .90 in a community sample. With high test-retest reliability .80 overall.

Demographic information and diagnosis information. This will include information about diagnosis asking individuals to state if they have a diagnosis of NEAD, Epilepsy + NEAD, FND. Confirming how the diagnosis was made, when and what medication, if any, they are taking. This will be based on similar information obtained in previous research such as Tallentire (2015).

Work and Social Adjustment Scale (WSAS; Mundt et al., 2002). The WSAS is a five-item scale which uses a zero to eight Likert scale to identify how much an individual finds their difficult impacts their life. The questions pertain to areas of work, social and home functioning. The scale is frequently used in mental health out-patient services and has been validated to be used with a wide variety of populations within the UK.

Gaining Informed Consent

An online consent form will be required to be completed by participants prior to the completion of the study. The participant information sheet will be provided prior to the completion of the consent form. Following the participants being shown the participation information sheet they will be asked to click through the consent form as a means of providing digital consent.

Data Collection

Recruitment will be completed online through online support groups, and social media such as Twitter and Facebook. Online data collection was selected as it can positively impact data collection, reaching a wider variety of individuals at reduced cost and burden to both participant and researcher (King et al., 2014). Tallentire (2015) demonstrated that on-line recruitment is successful for research with individuals with NEAD.

Data Storage

As per University policy, data will be stored on the University's secure server and held for 10 years. At that point the Research Director of the Lancaster University Doctorate in Clinical Psychology will arrange for the data to be deleted from the system. Digital copies of the consent forms will be stored on the secure server for ten years, and then deletion will be arranged by the Research Director.

Proposed Analysis

Quantitative analysis will be completed using multiple regression. Multiple regression was selected due to the nature of the design of the study, which utilises a single group design. A single group design was selected due to the novel nature of the research and to highlight individual psychological process that may be relevant in the NEAD population.

Practical Issues

There are no anticipated practical issues identified with this study. This study will use an on-line design to increase the access of participants who may not be accessing services. By utilising an online design the burden on participants will be reduced and financial and practical issues will be minimised. **Ethical Concerns**

There are no risks anticipated with participating in this study. Due to the nature of the questions being asked and the questionnaires selected it is not anticipated that difficult feelings will arise during the completion of this study. However, if individuals do become distressed it will be recommended both in the participant information sheet, which will appear on screen prior to obtaining consent and in the debriefing sheet following the study, that individuals contact their GP if distressing feelings arise.

Contact information for Mind and Rethink Mental illness will also be provided. The questionnaires which will be used have been selected based on their ease of understanding, previous use in the literature as well as the limited emotional and time burden they impose upon participants.

It is believed that this is a project involving straightforward issues which can be identified and managed routinely in accordance with standard research practice and existing guidelines. The lead researcher is a current trainee in Clinical Psychology, supervised by three experienced clinical researchers in research with people who may be experiencing distressing emotions, and specifically trained to conduct quantitative research. The data generated by this research will be treated anonymously and maintained according to the Good Clinical Practice Guidelines by the NIHR, and the Declaration of Helsinki published by the World Medical Association.

As this is an on-line study individuals will be provided with an option saying they do not want their data to be used following completion of the study.

Service User Involvement

NEADuk and FNDhope have been contacted to gain service user input. Clinicians working in the area have been involved in the planning of the project to identify areas which will be beneficial to clinicians and the population.

Dissemination Strategy

The results of this research study will be written up as a Doctorate in Clinical Psychology thesis. Following the submission of the thesis this project will seek publication in Epilepsy & Behaviour which has an impact factor of 2.332.

A summary flyer will be created which will be shared on Twitter and with the service user groups which have been involved. The supervisory team will have access to the dataset as needed.

Project timeline

Time	Project
June/July 2017	Submit documentation for ethical approval to the FHMREC
July 2017	Return of documentation, creation of On-line surveys
August 2017	Survey will be posted on-line using Twitter, facebook and NEAD support groups.
August – December 2017	Data collection and data entry to be completed as possible
December 2017–February 2018	Data Analysis
February- March 2018	Draft write-up of results and discussion
March – April 2018	Write-up of final version for submission at University
May 2018	Submit thesis to University and complete Viva
September 2018	Submit manuscript for publication

Participant Information Sheet

Psychological Mechanisms in Non-Epileptic Attack Disorder

My name is Tasha Cullingham and I am conducting a research project as part of the Doctorate in Clinical Psychology programme at Lancaster University, Lancaster, United Kingdom. This research is being supervised by Prof. Bill Sellwood and Dr. Fiona Eccles at Lancaster University and Dr. Antonia Kirkby at Salford Royal Hospital.

What is the study about?

In recent years, medical professionals have gotten better at identifying when someone is experiencing non-epileptic attacks. However, there is still lots of work to be done to find the best treatments for people with Non-Epileptic Attack Disorder (NEAD). The purpose of this study is to gain a better understanding of the psychological mechanisms involved in physical sensations that individuals with a diagnosis of NEAD feel. We are hoping that this will help us learn more about the psychological factors which contribute to experiencing a non-epileptic attack, so that in the future we can explore what types of psychological support will best help individuals with a diagnosis of NEAD.

Why have I been approached?

You have been approached because the study requires information from people aged 18 years and older who have a diagnosis of NEAD.

Do I have to take part?

No, it's completely up to you to decide whether or not you take part.

What will I be asked to do if I take part?

If you decide you would like to take part, you will be asked to complete an online questionnaire, which will ask about how you manage and think about your feelings, how often you experience physical sensations, your thinking style, the impact NEAD has on your daily life and demographic information. It will take approximately 10-20 minutes to complete the online questionnaire.

Will my data be Identifiable?

No one will know the information is yours, as the information you provide will be anonymous.

- At the end of the study, data will be kept securely on the university's secure server for ten years. At the end of this period, they will be destroyed.
- The dataset may be published; however, all data will be anonymous and no identifiable elements will be included.

What will happen to the results?

The results will be summarised and reported as part of a thesis within the Lancaster University Doctorate in Clinical Psychology programme. Following this, the report may be submitted for publication in an academic or professional journal. I will also be sharing a summary of the report online. The summary will never have specific information about you.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress whilst completing the questionnaire please stop, and contact the organisations included in the resources provided at the end of this sheet. In addition, please contact these organisations if you experience distress following participating in this study.

Are there any benefits to taking part?
Although you may find participating interesting, there are no direct benefits to taking part.

Who has reviewed the project?
This study has been reviewed and approved by the Lancaster University Faculty of Health and Medicine Research Ethics Committee.

Where can I obtain further information about the study if I need it?
If you have any questions about the study, please contact the lead researcher by post or email:

Tasha Cullingham
Trainee Clinical Psychologist
Faculty of Health and Medicine
Lancaster University
Lancaster, LA1 4YG
Email: T.Cullingham@lancaster.ac.uk

Complaints
If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, please contact Professor Bill Sellwood. If you wish to speak to someone outside of the Lancaster University Doctorate in Clinical Psychology Programme, you may also contact Professor Roger Pickup:

Professor Bill Sellwood
Programme Director
Doctorate in Clinical Psychology
Furness Building
Lancaster University
Lancaster, LA1 4YG
Phone: +44 (0)1524 593998
Email: b.sellwood@lancaster.ac.uk

Professor Roger Pickup
Associate Dean for Research
Faculty of Health and Medicine
Lancaster University
Lancaster, LA1 4YG
Phone: +44 (0)1524 593746
Email: r.pickup@lancaster.ac.uk

Resources in the event of distress
Should you feel distressed either as a result of taking part, or in the future, please contact your GP for support. In addition, the following resources may be of assistance

Rethink Mental Illness
Website: https://www.rethink.org

Mind for better mental health
Website: http://www.mind.org.uk

Consent Form

Psychological Mechanisms in Non-Epileptic Attack Disorder

We are asking if you would like to take part in a research project that explores psychological principles in Non-Epileptic Attack Disorder. Before you consent to participating in the study please read the information provided. If you have any questions or queries before taking part, please contact to the principal investigator, Tasha Cullingham at T.Cullingham@lancaster.ac.uk.

Please read the following statements and click on the option below to indicate that you are happy to take part in the study.

1. I confirm that I have read the participant information sheet and fully understand what is expected of me.
2. I understand that the questionnaire will include questions about how I deal with emotional situations and that although every care has been taken for these questions to be asked in a sensitive manner, they may be upsetting at times. I understand that I do not have to complete the questionnaire and that I am free to stop at any time, for any reason.
3. I understand that once I have submitted my anonymous responses it will not be possible to remove them.
4. I understand that my anonymous responses will be added to other participants' responses and may be published as part of an anonymous dataset and written up as a research report, which may be published.
5. I consent to Lancaster University keeping the anonymous data from the study for 10 years after the study has finished.

☐ I agree with the above statements and consent to participate in the current study

Eligibility

To be eligible to participate in this study you must be 18 years of age or older and experience seizures that have no identifiable biological cause. To be able to continue please check each box to confirm you are eligible to participate in this study.

☐ I am 18 years of age or older

☐ I have been diagnosed with seizures where there is no identifiable biological cause, such as Non-Epileptic Attack Disorder (NEAD), Psychogenic Non-Epileptic Seizures (PNES), Psychogenic Seizures, or Functional Seizures.

If you are younger than 18 years old or do not experience seizures that do not have a biological cause, unfortunately you are not eligible to participate in the current study. Thank you for your interest in this study.

Debrief Sheet
Psychological Mechanisms in Non-Epileptic Attack Disorder

Thank you for your time
Thank you for participating in this study. The information you have provided will be pooled with other peoples' responses and written up as a research report.

If you are feeling upset
Should you feel distressed either as a result of taking part, or in the future, please contact your GP for support. In addition, the following resources may be of assistance:

Rethink Mental Illness
Website: https://www.rethink.org

Mind for better mental health
Website: http://www.mind.org.uk

Have a complaint?
If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact Professor Bill Sellwood or if you want to speak to someone outside of the Lancaster University Doctorate in Clinical Psychology Programme, you may contact Professor Roger Pickup:

Professor Bill Sellwood
Programme Director
Doctorate in Clinical Psychology
Furness Building
Lancaster University
Lancaster, LA1 4YG
Phone: +44 (0)1524 593998
Email: b.sellwood@lancaster.ac.uk

Professor Roger Pickup
Associate Dean for Research
Faculty of Health and Medicine
Division of Biomedical and Life Sciences
Lancaster University
Lancaster, LA1 4YG
Phone: +44 (0)1524 593746
Email: r.pickup@lancaster.ac.uk

No longer want your data used?

If you have now decided that you no longer want the information you have provided to be used for research purposes, please indicate that below.
☐ Please **Delete** my data. I **do not want** my anonymous responses used for research

Demographics Form

Age	_____
Gender	_____
Country of residence	_____
Ethnicity	_____
Employment status	☐Student ☐Employed Full time ☐Employed Part time ☐Unable to work - receiving disability benefits ☐Signed off work- due to sickness ☐Unable to work– not receiving disability benefits ☐Full time unpaid parent or carer ☐Retired ☐Unemployed - looking for work ☐Unemployed - not looking for work ☐Currently on maternity or paternity leave ☐Other _____
Additional diagnosis (check all that apply)	☐Epilepsy ☐Functional Neurological Disorder ☐Depression ☐Anxiety ☐Personality disorder ☐Other _____
Approximate Age at time of diagnosis	_____
NEAD Diagnosis made by (check all that apply)	☐MRI ☐EEG and Video ☐By GP ☐In hospital ☐Other _____
I currently have NEA's	☐I am currently not experiencing non-epileptic attacks ☐I have attacks daily or every day ☐I have attacks less than five times per week ☐I have attacks 1-3 times per week ☐I have attacks 1-3 times per month ☐I have attacks yearly but not every month
Highest level of education	☐Left prior to exams (prior to completion of high school) ☐GCSEs or equivalent ☐A levels or equivalent (high school diploma) ☐Vocational training ☐Bachelor degree ☐Post graduate qualification

Work and Social Adjustment Scale

This section asks about how much your NEAD impacts your daily living.

Work and Social Adjustment Scale (WSAS)

Identifier _____ Date _____

People's problems sometimes affect their ability to do certain day-to-day tasks in their lives. To rate your problems look at each section and determine on the scale provided how much your problem impairs your ability to carry out the activity. This assessment is not intended to be a diagnosis. If you are concerned about your results in any way, please speak with a qualified health professional.

If you're retired or choose not to have a job for reasons unrelated to your problem, tick here ☐

	0 Not at all	1	2 Slightly	3	4 Definitely	5	6 Markedly	7	8 Very severely
1	Because of my [problem] my **ability to work** is impaired. '0' means 'not at all impaired' and '8' means very severely impaired to the point I can't work.								
2	Because of my [problem] my **home management** (cleaning, tidying, shopping, cooking, looking after home or children, paying bills) is impaired.								
3	Because of my [problem] my **social leisure activities** (with other people e.g. parties, bars, clubs, outings, visits, dating, home entertaining) are impaired.								
4	Because of my [problem], my **private leisure activities** (done alone, such as reading, gardening, collecting, sewing, walking alone) are impaired.								
5	Because of my [problem], my ability to form and maintain **close relationships** with others, including those I live with, is impaired.								

Acceptance and Action Questionnaire Two

This section asks questions about how you feel about your thoughts and feelings.

AAQ-II

Below you will find a list of statements. Please rate how true each statement is for you by using the scale below to fill in your choice.

1	2	3	4	5	6	7
never true	very seldom true	seldom true	sometimes true	frequently true	almost always true	always true

1. My painful experiences and memories make it difficult for me to live a life that I would value.
2. I'm afraid of my feelings.
3. I worry about not being able to control my worries and feelings.
4. My painful memories prevent me from having a fulfilling life.
5. Emotions cause problems in my life.
6. It seems like most people are handling their lives better than I am.
7. Worries get in the way of my success.

TOTAL

Mindful Attention Awareness Scale

This section asks about how mindful you are and how much attention you pay in your daily life.

Day-to-Day Experiences

Instructions: Below is a collection of statements about your everyday experience. Using the 1-6 scale below, please indicate how frequently or infrequently you currently have each experience. Please answer according to what *really reflects* your experience rather than what you think your experience should be. Please treat each item separately from every other item.

1 Almost Always	2 Very Frequently	3 Somewhat Frequently	4 Somewhat Infrequently	5 Very Infrequently	6 Almost Never

I could be experiencing some emotion and not be conscious of it until some time later.	1	2	3	4	5	6
I break or spill things because of carelessness, not paying attention, or thinking of something else.	1	2	3	4	5	6
I find it difficult to stay focused on what's happening in the present.	1	2	3	4	5	6
I tend to walk quickly to get where I'm going without paying attention to what I experience along the way.	1	2	3	4	5	6
I tend not to notice feelings of physical tension or discomfort until they really grab my attention.	1	2	3	4	5	6
I forget a person's name almost as soon as I've been told it for the first time.	1	2	3	4	5	6
It seems I am "running on automatic," without much awareness of what I'm doing.	1	2	3	4	5	6
I rush through activities without being really attentive to them.	1	2	3	4	5	6
I get so focused on the goal I want to achieve that I lose touch with what I'm doing right now to get there.	1	2	3	4	5	6
I do jobs or tasks automatically, without being aware of what I'm doing.	1	2	3	4	5	6
I find myself listening to someone with one ear, doing something else at the same time.	1	2	3	4	5	6
I drive places on 'automatic pilot' and then wonder why I went there.	1	2	3	4	5	6
I find myself preoccupied with the future or the past.	1	2	3	4	5	6
I find myself doing things without paying attention.	1	2	3	4	5	6
I snack without being aware that I'm eating.	1	2	3	4	5	6

Difficulties in Emotional Regulation Scale

This section asks in how you deal with and understand your emotions.

Difficulties in emotional regulation scale

	Almost Never (0–10%)	Some-times (11–35%)	About Half Of the Time (36–65%)	Most of the Time (66–90%)	Almost Always (91–100%)
1. I pay attention to how I feel	1	2	3	4	5
2. I have no idea how I am feeling	1	2	3	4	5
3. I have difficulty making sense out of my feelings	1	2	3	4	5
4. I care about what I am feeling	1	2	3	4	5
5. I am confused about how I feel	1	2	3	4	5
6. When I'm upset, I acknowledge my emotions	1	2	3	4	5
7. When I'm upset, I become embarrassed for feeling that way	1	2	3	4	5
8. When I'm upset, I have difficulty getting work done	1	2	3	4	5
9. When I'm upset, I become out of control	1	2	3	4	5
10. When I'm upset, I believe that I will end up feeling very depressed	1	2	3	4	5
11. When I'm upset, I have difficulty focusing on other things	1	2	3	4	5
12. When I'm upset, I feel guilty for feeling that way	1	2	3	4	5
13. When I'm upset, I have difficulty concentrating	1	2	3	4	5
14. When I'm upset, I have difficulty controlling my behaviors	1	2	3	4	5
15. When I'm upset, I believe there is nothing I can do to make myself feel better	1	2	3	4	5
16. When I'm upset, I become irritated with myself for feeling that way	1	2	3	4	5
17. When I'm upset, I lose control over my behavior	1	2	3	4	5
18. When I'm upset, it takes me a long time to feel better	1	2	3	4	5

Cognitive Fusion Questionnaire

This section asks about how much your thoughts impact you, and how powerful your thoughts feel.

CFQ

Below you will find a list of statements. Please rate how true each statement is for you by circling a number next to it. Use the scale below to make your choice.

1	2	3	4	5	6	7
never true	very seldom true	seldom true	sometimes true	frequently true	almost always true	always true

1. My thoughts cause me distress or emotional pain	1	2	3	4	5	6	7
2. I get so caught up in my thoughts that I am unable to do the things that I most want to do	1	2	3	4	5	6	7
3. I over-analyse situations to the point where it's unhelpful to me	1	2	3	4	5	6	7
4. I struggle with my thoughts	1	2	3	4	5	6	7
5. I get upset with myself for having certain thoughts	1	2	3	4	5	6	7
6. I tend to get very entangled in my thoughts	1	2	3	4	5	6	7
7. It's such a struggle to let go of upsetting thoughts even when I know that letting go would be helpful	1	2	3	4	5	6	7

The Physical Health Questionnaire-15

This section asks about your physical symptoms and how much they bother you.

PHYSICAL SYMPTOMS (PHQ-15)

During the past 4 weeks, how much have you been bothered by any of the following problems?

	Not bothered at all (0)	Bothered a little (1)	Bothered a lot (2)
a. Stomach pain	☐	☐	☐
b. Back pain	☐	☐	☐
c. Pain in your arms, legs, or joints (knees, hips, etc.)	☐	☐	☐
d. Menstrual cramps or other problems with your periods ***WOMEN ONLY***	☐	☐	☐
e. Headaches	☐	☐	☐
f. Chest pain	☐	☐	☐
g. Dizziness	☐	☐	☐
h. Fainting spells	☐	☐	☐
i. Feeling your heart pound or race	☐	☐	☐
j. Shortness of breath	☐	☐	☐
k. Pain or problems during sexual intercourse	☐	☐	☐
l. Constipation, loose bowels, or diarrhea	☐	☐	☐
m. Nausea, gas, or indigestion	☐	☐	☐
n. Feeling tired or having low energy	☐	☐	☐
o. Trouble sleeping	☐	☐	☐

(For office coding: Total Score T_____ = _____ + _____)

Lancaster University Data Management

We'd encourage you to use the online tool DM online (https://dmponline.dcc.ac.uk/) which provides guidance and additional features such as sharing and export options.

1. Data Collection

- Data will be collected in the form of seven brief On-line questionnaires
- For sufficient power a minimum of 107 individuals will be asked

2. Documentation and Metadata

- Data will be downloaded from Qualtrics and entered into SPSS. Participants will be allocated a participant number. No identifiable information will be kept in the SPSS file. The file will be password protected and stored on a secure server.

3. Storage, Backup and Security

- A backup of the data will be kept on a solid state encrypted and password protected USB drive. Only the lead researcher will be aware of the passwords. The data custodian will be Dr. Bill Sellwood, supervisor.

4. Ethics and Legal Compliance

- There are not believed to be any legal or ethical concerns with the data obtained in this project.

5. Selection and Preservation

- As per university policy, data will be stored on the University's secure server and held for 10 years. At that point the Research Director of the Lancaster University Doctorate in Clinical Psychology will arrange for the data to be deleted from the system. Digital copies of the consent forms will be stored on the secure server for ten years, and then deletion will be arranged by the Research Director

6. Data Sharing

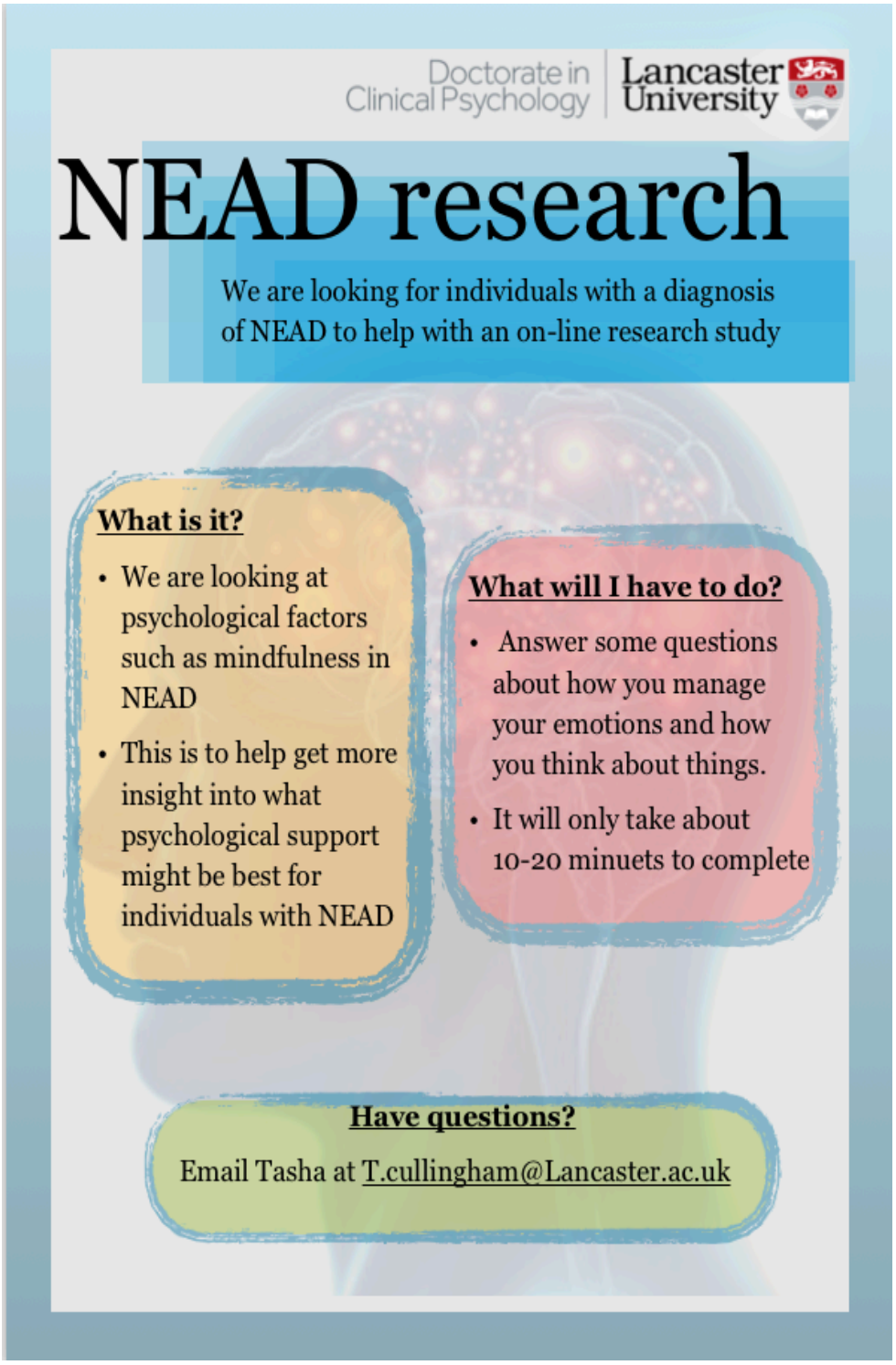
- The anonymous database will be made available as per open access

7. Responsibilities and Resources

- The lead researcher, Tasha Cullingham
- Resources, such as a secure USB and encrypted university H drive have already been put in place by Lancaster Doctorate in Clinical Psychology.

Advertising Material

Facebook Poster



Twitter Banner