The University Of Sheffield.

Are Personality Traits and Self-Compassion Associated with Adjustment in Seizure Disorders?

Submitted by

Stephanie Clegg

Submitted for the award of

Doctor of Clinical Psychology

University of Sheffield

May 2018

Declaration

This thesis is submitted for the Doctorate in Clinical Psychology at the University of Sheffield. It has not been submitted for any other degree or to any other academic institution.

Structure and Word Count

Literature review	7970
Including tables and references	14612
Research report	7980
Including tables and references	11321
Total word count	15950
Including tables and references	25933

Abstract

Literature Review

The aim of this review was to collate and critically evaluate research investigating the relationship between the 'Big 5' personality traits and things that may be related to adjustment e.g. anxiety (clinical correlates) in people with epilepsy. Focus was also placed on the identification of personality traits and clinical correlates included in relevant studies, and how these were measured. Studies were identified through electronic database searches using terms relating to epilepsy, the 'Big 5' personality traits and clinical correlates. Sixteen articles of good to excellent quality were included in the review. Neuroticism was the most commonly included 'big 5' personality trait, followed by extraversion, most commonly assessed by measures called the Neo Five Factor Inventory and the Eysenck Personality Questionnaire. These personality traits were correlated with items that feed into six main categories: (1) mental health, (2) quality of life, (3) adjustment and changes to identity, (4) subjective complaints, (5) objective cognitive performance, (6) seizure variables. Findings suggest higher neuroticism levels were correlated with poorer mental health, poorer quality of life, poorer adjustment, and higher levels of health complaints in epilepsy populations. Higher levels of extraversion were shown to be associated with a higher quality of life. This review cannot determine whether these findings are casual or directional, as most of the studies were cross-sectional. Recommendations for clinical practice and future research are discussed including offering psychotherapy focussing on managing the characteristics of neuroticism.

Research Report

The aim of this study was to investigate whether self-compassion, gratitude and perfectionism were associated with adjustment in people with epilepsy (PWE) and people with non-epileptic attack disorder (PWNEAD). Adjustment was measured via coping efficacy (how well someone thinks they are coping with their illness), quality of life, anxiety and depression. Participants including PWE (N=74), PWNEAD (N = 46), and controls (N=89), completed questionnaires about their self-compassion, personality traits, coping efficacy, quality of life, anxiety and depression levels. These participants were recruited from outpatient seizure clinics and online. Overall self-compassion was shown to be associated with better adjustment in PWE and PWNEAD. Self-compassion was found to be negatively related to anxiety and depression in PWE, PWNEAD and controls; and positively related to coping efficacy in PWE and PWNEAD. Self-compassion was also found to be positively related to quality of life in PWE and controls; however, this relationship was not found in PWNEAD. Gratitude was positively related to coping efficacy in PWE and PWNEAD but not in controls. Perfectionist strivings (setting high standards for yourself) were positively related to coping efficacy in PWE only. Further research is required to develop understanding in to the relationship between self-compassion, personality traits and adjustment, focussing on causality and the mediating factors. Offering psychotherapies that focus on the development of self-compassion and gratitude may decrease distress in PWE and PWNEAD, and improve their ability to adjust to their condition.

Acknowledgments

I would first like to thank the participants who agreed to take part in this research, without your time and interest this thesis would not have been possible.

Thank you to my supervisors, Prof. Markus Reuber and Dr. Fuschia Sirois, for your helpful guidance and support throughout this research project. I would also like to thank the staff at the seizure clinics and research and development department. Your help throughout the ethical approval and recruitment process was greatly appreciated.

I would like to take this opportunity to also thank my fellow trainees for your continued support and camaraderie throughout the doctoral journey.

Finally I would like to thank all of my wonderful family and friends outside of the psychology world, for your continued patience, support and humour throughout my years of training. Last but not least, a big thank you to my husband for believing in me always.

Contents

Appendices

Section One: Literature Review

Personality Traits and Indicators of Adjustment (Clinical Correlates) in Epilepsy: A Systematic Review

Abstract

Objectives. The ‘Big 5’ personality traits are associated with indicators of adjustment in different chronic illness populations. The aim of this review was to systemically collate and critically evaluate research investigating the relationship between the ‘Big 5’ personality traits and clinical indicators of adjustment (clinical correlates) in people with epilepsy. Focus was also placed on the identification of personality traits and clinical correlates included in relevant studies, and how these were measured.

Method. Searches of Medline, PsychInfo, CINAHL, Scopus and Cochrane Library were conducted. Search concepts relating to epilepsy, the ‘Big 5’ personality traits and clinical correlates were included.

Results. Sixteen articles of good to excellent quality were included in data synthesis. The majority of the studies were cross-sectional. Neuroticism was the most commonly included ‘big 5’ personality trait, followed by extraversion, most commonly measured by the NEO-FFI and EPQ. These personality traits were correlated with items that feed into six main categories: (1) mental health, (2) quality of life (QoL), (3) adjustment and changes to identity, (4) subjective complaints, (5) objective cognitive performance, (6) seizure variables. Findings suggest higher neuroticism levels were correlated with poorer mental health, poorer QoL, poorer adjustment and higher subjective complaints in epilepsy populations. Higher levels of extraversion were shown to be associated with a higher QoL.

Conclusions. This review cannot determine whether these associations are casual. Longitudinal research is needed to further investigate these associations. Comparing results to well matched control samples would provide the means to derive more epilepsy-specific conclusions.

Practitioner Points

- Offering psychotherapy focussing on managing the characteristics of neuroticism (i.e. proneness to experiencing negative emotions and being easily overwhelmed by stress) may be beneficial e.g. mindfulness based cognitive therapy or dialectical behaviour therapy skills.

- Personality screens for individuals at epilepsy diagnosis may help to identity potential individuals 'at risk' of mental health difficulties.

- Personality screens may be helpful for clinicians to be aware of individuals who are likely to present with more or less subjective complaints.

- Future reviews should include meta-analysis to compare the magnitude of associations found between personality traits and clinical correlates in the epilepsy and general population.

Introduction

Personality and Epilepsy

Epilepsy is a chronic condition characterised by recurrent seizures caused by abnormal electrical discharges in the brain. The notion of an 'epileptic personality' has been researched for many decades and was generally thought to consist of explosive impulsivity, affective viscosity (the tendency to prolong interactions with others), and egocentricity (overriding concern with the self) (Baxendale, 2014). Research has shown an increased prevalence of personality disorders in epilepsy populations (Bear & Fedio, 1977; Schwartz & Cummings, 1988; Swinkels et al., 2003) and in the 20th century Geschwind (1979) introduced the idea of an 'interictal personality disorder'. However, the 'epileptic personality' is now widely considered to be an outdated concept due to concerns of over-generalisation and a dearth of robust evidence to link the proposed behavioural features and epilepsy (Benson, 1991; Baxendale, 2014). Researchers have therefore turned their attention towards a dimensional trait model to investigate personality in individuals with seizure disorders (Reuber et al., 2003; Zimmerman & Endermann, 2008). This reflects a shift towards dimensional trait models in the overall personality literature. A dimensional interpretation of personality is now contained in the Diagnostic and Statistical Manual of Mental Disorders-5th edition (DSM-V; 2013) as an alternative understanding to the categorical approach presented in the DSM-IV (2000). Accordingly, one aspect of this review will be to gather information on how personality is currently being measured in the epilepsy literature.

The ‘Big 5’ Personality Traits

The most widely used and accepted dimensional trait model of personality is Costa and McCrae’s (1992) five factor model. Their work adopts a contemporary approach assimilating more than four decades of factor analytic personality research in psychiatric and community populations in various cultural backgrounds. This conceptualization proposes that there are five key higher order, superordinate dimensions, the ‘Big 5’, which provide a comprehensive and hierarchically organized overview of personality: Neuroticism (prone to experiencing negative emotions and being easily overwhelmed by stress), extraversion (being sociable and experiencing positive emotions), conscientiousness (acting in an organized and disciplined manner), agreeableness (having a trusting, and cooperative nature), and openness to experience (taking a curious and unconventional approach) (Costa & McCrae, 1992). The five factor traits are proposed to be biologically determined, temporally stable, and yet still reciprocally affected by life circumstances and social contexts (McCrae et al., 2000). Therefore, psychological adjustment to a chronic illness, such as epilepsy, may be influenced by longstanding and relatively fixed patterns of thinking, emotional reactions and behaviours reflected in the ‘Big 5’ personality factors (Margolis, Nakhutina, Schaffer, Grant, & Gonzalez, 2018).

Personality and Chronic Illnesses

A growing body of research has focussed on whether personality plays a role in the predisposition for and outcome of chronic physical illness (Erlen et al., 2011). Aldwin, Spiro, Levenson, and Cupertino (2001) suggest that personality traits underlie stable patterns of emotional and behavioural function that affect risk of developing chronic illnesses. They also suggest that personality traits can influence how one

perceives their own health and manages their symptoms and treatment, thereby affecting outcomes. The most salient personality traits investigated within chronic illness populations have been neuroticism and conscientiousness (Erlen et al., 2011). Research has shown a relationship between high levels of neuroticism, low levels of conscientiousness and mortality in individuals with diabetes and renal disease (Brickman, Yount, Blaney, Rothberg, & De-Nour, 1996; Christensen et al., 2002). There are also studies showing that high agreeableness and low neuroticism predict self-rated health in arthritis and irritable bowel disease, which is itself a predictor of mortality and morbidity (Sirois, 2015). Neuroticism has been associated with poor adjustment, poor health-related quality of life (HRQoL) and poor treatment adherence among many chronic illness populations (Lawson, Bundy, Belcher, & Harvey, 2010; Poppe, Crombez, Hanoulle, Vogelaers, & Petrovic, 2012; Bruce, Hancock, Arnett, & Lynch, 2010). Ibrahim, Teo, Che-Din, Abdul-Gafor and Ismail (2015) reported that that extraversion was positively associated to physical HRQoL, whereas neuroticism was negatively associated with poorer mental HRQoL in people with kidney disease. Furthermore, conscientiousness has been found to predict self-care in individuals awaiting renal transplantation (Horsburgh, Beanlands, Locking-Cusolitto, Howe, & Watson, 2000), and good adjustment in people with diabetes and multiple sclerosis (MS) (Lawson et al., 2010; Rassart et al., 2014; Bruce et al., 2010).

Coping has been implicated as an exploratory factor in the relationship between personality traits and illness adjustment (Helgeson & Zajdel, 2017). One study showed that those who were high in neuroticism and low in conscientiousness engaged in avoidant coping, which was in turn linked to poor adjustment (Rassart et al., 2014). Another study showed that the relation between neuroticism and poor health outcomes was explained by a lack of acceptance (Poppe et al., 2012). Ratsep, Kallasmaa, Pulver and Gross-Paju (2000) found that neuroticism was associated with emotion-focussed

coping whereas agreeableness was associated with avoidance-oriented coping in people with MS. Alternatively, differences in illness adjustment may be explained by the role of chronic illness in self-identity (Wilson et al., 2009). Individuals with chronic illness may view themselves as inferior and unable to fulfil their desired roles (Tedman, Thorton, & Baker, 1995). As health status is a key aspect of self-identity (Kroger, 2007), and health status is associated with personality traits (Watson & Clarke, 1992), it is possible that the relationship between self-identity and chronic illness is mediated by personality traits.

Living with epilepsy has been associated with high levels of anxiety and depression (Hermann, Seidenberg, & Bell, 2000; Lacey et al., 2016), psychosocial difficulties, reduced quality of life (QoL) and low levels of self-confidence and personal autonomy (Baker, 2002). However, epilepsy is a very heterogeneous disorder and there is considerable variability in the extent to which individuals with epilepsy experience difficulties with psychosocial functioning and mechanisms underpinning these associations, including personality traits, are underexplored (Goldstein, Holland, Soteriou, & Mellers, 2005).

The Current Review

There is a plethora of literature into the associations between the 'Big 5' personality traits, adjustment and outcomes in different chronic illness populations. However, the relationship between the 'Big 5' personality traits and adjustment in epilepsy is far from clear. This is due to the lack of systematic reviews focussing on these variables and the historical focus on categorical approaches to personality (including personality disorders) in the epilepsy population. In order to address this shortfall of the previous literature the current review aims to systematically collate and

critically evaluate available published research investigating the relationship between the 'Big 5' personality traits and clinical indicators of adjustment (e.g. QoL, anxiety, depression), herein referred to as 'clinical correlates' (CC), in people with epilepsy. The review has five main objectives, presented in Table 1.

Table 1

Five main objectives of review

	Objective
(i)	To identify which of the 'Big 5' personality factors are being included in research that links personality with CC in epilepsy samples, and to assess how these personality factors are being measured.
(ii)	To identify the clinical indicators of adjustments (CCs) being examined in association with the 'Big 5' personality factors, and to assess how these clinical indicators are being measured.
(iii)	To identify the strength and direction of the relationships between 'Big 5' personality factors and CC.
(iv)	To provide a methodological critique of studies.
(v)	To make clinical and research recommendations.

Method

Eligibility Criteria

Studies were included in the review if they met the following criteria: (i) female or male adult (>16years) patient participants with a diagnosis of epilepsy, (ii) measured one or more of the 'Big 5' personality traits (neuroticism, extraversion, openness, agreeableness and conscientiousness) using a valid self-report measure, (iii) measured a CC (e.g. anxiety, depression, QoL) using a reliable self- report measure (i.e. in a way that could be replicated), (iv) published in a peer reviewed journal article, (v) written in English. No restrictions regarding date of publication, type of epilepsy or setting were employed. As the review focused on the association of CCs with personality "traits" (namely the higher order 'Big 5' traits), any measures that produced personality "profiles", comprising of both personality characteristics and psychopathology, e.g. MMPI, were excluded from the review.

Information Sources

The following databases: Medline, PsycINFO, Scopus, Cochrane Library and The Cumulative Index to Nursing and Allied Health Literature (CINAHL) were searched during March 2018. No date restriction was placed on the search. References from relevant articles were reviewed to identify additional papers. Grey literature was not included due to time and resource constraints.

Search Strategy

Preliminary search concepts were developed using PICO (population, intervention, comparator and outcome) criteria (Moher et al., 2015). Concepts relating

to epilepsy (population), ‘the big five’ personality traits (intervention/focus) and CCs (outcomes) were included. No search concepts were included regarding comparator or study design. Appropriate truncation was applied to relevant search terms. Thesaurus-based expansion was carried out on all terms via explosion of Medical Subject Headings (MeSH) categories in Medline and PsycINFO. Relevant MeSH terms were included in the final search. Boolean operators ‘AND’ and ‘OR’ were used to combine key words. The full search strategy is shown in Table 2.

Table 2

Final search strategy

1	“Big 5”	ti, ab
2	“Big five”	ti, ab
3	“NEO five-factory inventory”	ti, ab
4	“NEO-FFI-3”	ti, ab
5	extravert*	ti, ab
6	agreeable*	ti, ab
7	open*	ti, ab
8	conscientious*	ti, ab
9	neuroticism	ti, ab
10	1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9	ti, ab
11	outcome*	ti, ab
12	“quality of life”	ti, ab
13	symptom*	ti, ab
14	adjust*	ti, ab
15	severity	ti, ab
16	frequency	ti, ab
17	depress*	ti, ab
19	anxiety	ti, ab
20	anxious	ti, ab
21	coping	ti, ab
22	stress	ti, ab
23	11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19OR 20 OR 21 OR 22	ti, ab
24	epilep*	ti, ab
25	seizure*	ti, ab
26	24 OR 15	ti, ab
27	10 AND 23 AND 26	ti, ab

Study Selection

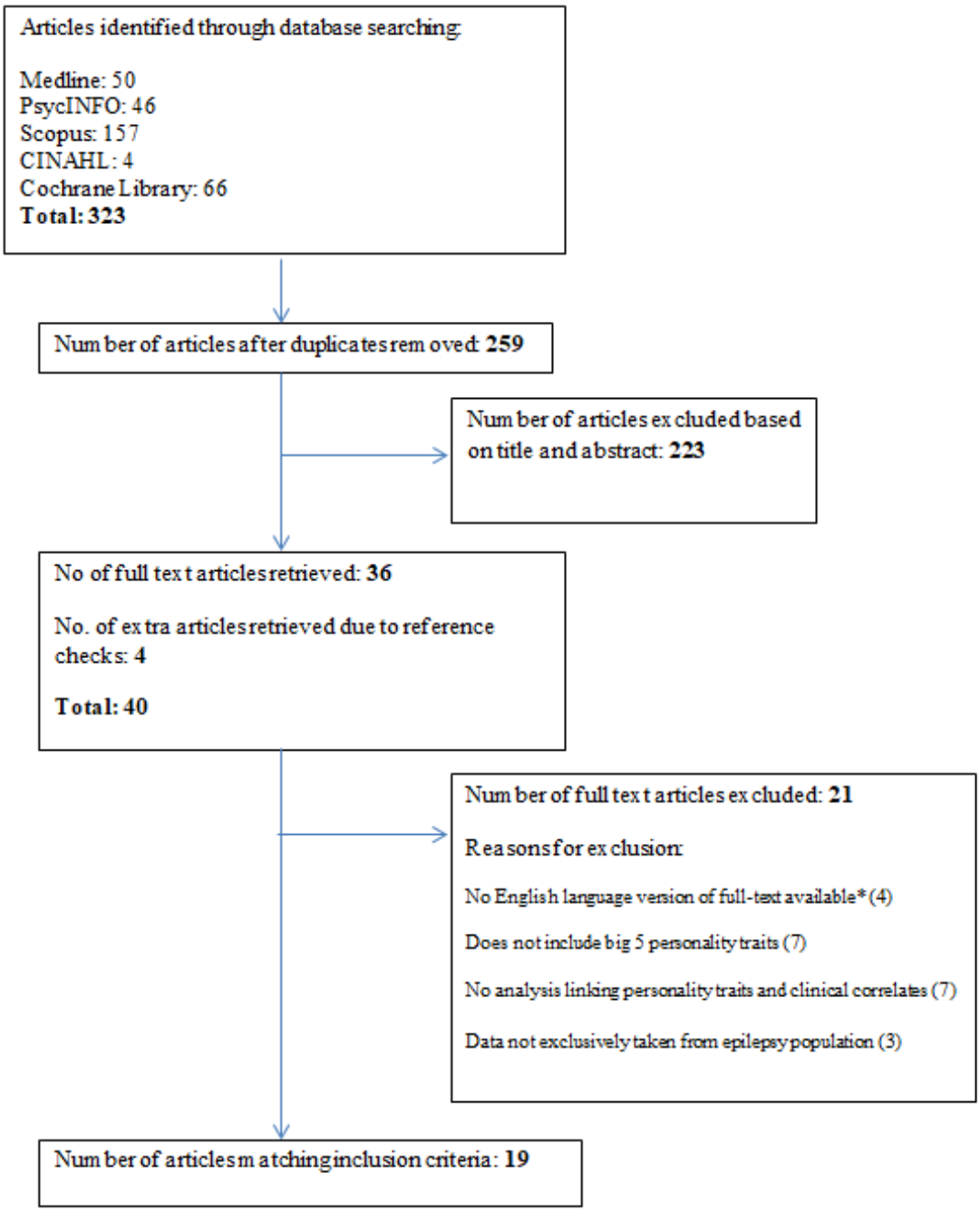
The database search produced 323 results. Of these results 64 were duplicates and therefore removed. All titles and abstracts were first reviewed for relevance before all relevant full text articles obtained. Reasons for exclusion of full text articles and an overview of article screening can be found in Figure 1. Nineteen full text articles met eligibility criteria for the review.

Quality Appraisal

The Downs and Black (1998; Appendix A) checklist was used to score the quality of included studies. Evidence supports the checklist's internal consistency, test-retest and interrater reliability, face and criterion validity (Downs & Black, 1998). This checklist provides an overall methodological quality score for each outcome study from a list of 27 items. The scoring criteria for item 27 has recently been simplified; awarding a score of one or zero depending on whether a power calculation was conducted and the study adequately powered to detect a significant treatment effect (Samoocha, Bruinvels, Elbers, Anema, & van der Beek, 2010). The original Downs and Black (1998) checklist was created to appraise both randomised and non-randomised trials. As the current review consists of cross-sectional and pre- post studies, as opposed to trials, the checklist has been adapted appropriately and irrelevant items omitted. The overall quality score has therefore been computed as a percentage of available items. The higher the percentage the higher the methodological quality of the paper.

Figure 1

PRISMA flow chart of article selection



**Full-text versions of Okazaki et al. (2018), Mao et al. (2012), Gonzalez, Fabelo, Gonzalez and Iglesias (2010) and Zhang, Li and Deng (2004) were unavailable in English. Authors were contacted however no English language full-text versions were received. It is likely that these studies would have contributed to the results of this systematic review.*

On the original Downs and Black checklist (1998) an overall methodological quality score of 19 points or more identifies studies with high methodological quality (O'Connor et al., 2015). This equates to 68% out of a possible score of 28 (item 5 offers 2 points). Therefore in this review studies with a higher rating than 68% will be considered to have high methodological quality. This process was completed by the author and an independent rater reviewed 20% (4) of the papers. There was a high inter-rater reliability (84% compatibility) and any disagreements were discussed until a consensus was achieved. This appraisal was carried out to assess the overall quality of the literature published within this area. Studies with a quality score of less than 68% were excluded from the synthesis of results due to low methodological quality.

Data Extraction

Data describing study characteristics including study design; samples characteristics (including setting); 'Big 5' personality trait(s) and related measure; CC and related measure; analysis pertaining to personality trait(s) and CC; and findings were extracted from studies.

Data Synthesis

Data was synthesised around the main aims of the review: Identification of the 'Big 5' personality factors, identification of CCs, identification the strength of the relationship between 'Big 5' personality factors and CCs, and providing a methodological critique of studies included. Clinical and research recommendations are provided in the discussion.

Results

Study Characteristics

Data extraction can be found in Table 3. Fifteen studies reported cross-sectional data. This included Wilson et al. (2009) who conducted a pre-post- surgery study, but presented only cross-sectional pre- surgery data in this article. Four studies reported pre-post- surgery data; three of which had one post-surgery time point at 12 months after surgery (Canizares et al., 2000; Witt et al., 2008; Huang et al., 2014) and one (Wilson et al., 2009) that included 3 post-surgery time points at 1- 3- and 12-months after surgery.

The studies included in this review were conducted in many different countries including Germany (n=5), The Netherlands (n=4), The United Kingdom (n=2), Australia (n=2), Tasmania (n=1), United States of America (n=1), Nigeria (n=1), Spain (n=1), China (n=1) and Canada (n=1). Overlapping data sets were present in two sets of two articles (Wilson et al., 2009 and Wilson et al., 2010; Endermann & Zimmerman, 2009 and Zimmerman & Endermann, 2008). As they reported on different aspects of the data, these results were included in the review however the common dataset was acknowledged and caution applied when interpreting results. Not double counting participants form the repeated cohorts, this review includes 2,438 participants with epilepsy with sample sizes ranging from small (n=33) to large (n=440). Overall the proportion of female participants was quite similar to that of male participants (% female: range 22-75%, median 50.5%), the mean age of participants ranged from 26-52 years of age (median 36.5). Participants included in the review had been diagnosed with many different types of epilepsy including focal and generalised epilepsies; well-controlled and medically refractory epilepsy.

Methodological Quality

Quality appraisal of each study can be found in Table 4. No studies satisfied all of the quality criteria. The quality of included articles ranged from low quality (45%: Wilson et al., 2010) to high quality (88%: Lacey et al., 2016; Molleken et al., 2010; Olley, 2001) however the majority received a rating of 68% or above. Only two articles (Margolis et al., 2018; Olley, 2001) reported using an adequately powered sample size, whereas others did not report a power analysis. For studies relating to epilepsy surgery patients, the source population *(item 13)* was considered to be 'epilepsy surgery candidates' rather than 'general epilepsy population' if the article made this distinction clear in its aims and conclusions.

Four papers (Standage & Fenton, 1975; Vermeulen et al., 1993; Zhu et al., 1998; Wilson et al., 2010) failed to score above 68% for methodological quality. Standage & Fenton (1975), Vermeulen et al. (1993) and Zhu et al. (1998) were therefore excluded from the data synthesis due to low methodological quality. Wilson et al. (2010) references their previously published paper (Wilson et al., 2009; 69% appraisal score), to provide methodological detail regarding the study to the reader. This confirms the methodological robustness of the study and findings from this 2010 paper were used in data synthesis.

Table 3
Data Extraction

Author (Year) Country	Study Design	Sample	'Big 5' Personality Trait and measure (with references)	CC and measure (with references)	Analysis pertaining to personality traits and CC	Personality findings
1 Endermann & Zimmerman (2009) (Germany)	Cross-sectional Self-reported and carer-reported data collected. This review takes the information from self-reported data only.	N=36 (Young adults with epilepsy and mild cognitive impairments) Short-term residential rehabilitation centre %female:39 Mean age: 26	Neuroticism (Neo Five Factor Inventory; NEO-FFI; Costa and McCrae (1989))	Health related QoL (HRQoL) (QoL in epilepsy scale, QOLIE-31; Cramer et al. 1998). Anxiety and depression (Hospital Anxiety and Depression Scale; HADS; Dutch version; Hermann, Buss, & Snaith, 1995).	Pearson's correlations Stepwise regression analysis	A significant positive correlation was found between neuroticism scores and anxiety scores. A significant positive correlation was found between neuroticism scores and depression scores. A significant negative correlation was found between neuroticism scores and HRQoL score (high neuroticism related to lower HRQoL) Stepwise regression showed neuroticism was an independent predictor for anxiety, depression and HRQoL scores.
2 Helmstaedter & Witt (2012) Germany	Cross-sectional	N= 428 (frontal (16%) and temporal lobe (84%) epilepsies) Pre- surgical assessment (unable to determine inpatient/ outpatient setting) %female: 52 Mean age: 39	Neuroticism, Extraversion (Fragebogen zur Personlichkeit bei zerebralen Erkankungen; FPZ; Helmstaedter, Gleissner and Elger (2000))	Depression (BDI-II; Beck & Steer, 1987). Cognitive status (Battery of psychometric tests to evaluate: attention, language, memory, visuoconstruction *Full details given in subsequent paper (Clusmann et al., 2002)*	Pearson's correlation	Depression scores show high, positive correlations to neuroticism scales and minor correlation to the introversion scales. A positive correlation was found between introversion and better cognitive status scores. **The paper does not state if these correlations are statistically significant**

3 Hendriks, Aldenkamp, Van der Vlugt, Alpherts, & Vermeulen (2002). The Netherlands	Cross-sectional	N=252 (medically refractory seizures) Three epilepsy centres(Unable to determine inpatient/outpatient centre) %female: 45 Mean age: 36	Neuroticism (ABV-Amsterdamse Biografische Vragenlijst; Wilde (1970))	Subjective memory complaints (Geheugen Klachten Lijst voor Epilepsie; GKLE; Vermeulen, Aldenkamp, & Alpherts, 1993).	Pearson's correlation	A significant weak positive correlation was found between neuroticism and subjective memory complaints (including memory for semantic structures). When entered into a multiple regression analysis the contribution of neuroticism to overall variance of total memory score was modest (11%).
4 Lacey, Salzberg, & D'Souza (2016). Tasmania	Cross-sectional	N= 440 (any epilepsy diagnosis) Primary care mail survey % female: 52 Mean age: 52	Neuroticism (International Personality Item Pool (IPIP-N): Neuroticism Scale; Goldberg, et al. 2006)	Depression (Centre for epidemiologic studies depression scale; CES-D; Jones et al. 2005)	Spearman's correlation Multivariate analysis using general linear regression models	A strong, positive correlation was found between depressive symptoms and neuroticism. Linear regression modelling showed neuroticism was the primary predictor for depression (accounting for 52% of variance).
5 Margolis, Nakhutina, Schaffer, Grant, Gonzalez (2018). New York, United States of America.	Cross-sectional	N=60 (intractable seizures) Outpatient clinic %female:62 Mean age: 42 Racially/ethnically diverse adults (79% black, 20% Hispanic/Latino, 8% White)	Neuroticism, Extraversion (NEO-FFI)	Epilepsy Stigma (Epilepsy stigma scale; ESS; Dilorio et al. 2003). Epilepsy related social well-being (QoL inventory in epilepsy; QOLIE- 89; Devinsky et al. 1995).	Ordinary least-squares (OLS) regression	Higher levels of neuroticism and lower levels of extraversion were significantly and independently associated with greater perceived stigma. Stigma, in turn, was significantly and independently associated with poorer social wellbeing. Neuroticism and Extraversion were indirectly associated with social well-being though their respective associations with perceived stigma.

6 Molleken, Richte-Appelt, Stodieck, & Bengner (2010). Germany	Cross-sectional	N=49 (15 generalised epilepsy, 34 focal epilepsy) Inpatient epilepsy clinic %female: 47 Mean age:34	Neuroticism, Extraversion, Openness Agreeableness, Conscientiousness (NEO-FFI)	Sexual QoL (SQOL; Derogatis Interview for sexual function-Self report Inventory; DISF-SR; Derogatis, 1997). Life Satisfaction (Life satisfaction questionnaire; Fahrenberg, Myrtek, Schumacher, & Brahler, 2000)	Stepwise backward multiple linear regression analysis (SQOL) Pearson's correlation (Life satisfaction)	Lower extraversion and female sex were factors associated with decreased SQOL. Together they explained 22% of the overall variance f SQOL when adjusted scores were entered and 29% when raw scores were entered into the regression model. Life satisfaction correlated negatively with neuroticism and positively with extraversion, agreeableness and conscientiousness.
7 Olley (2001) Nigeria	Cross-sectional	N=264 (any clinically diagnosed epilepsy) Outpatient clinics %female: 41 Mean age: 33	Neuroticism (Crown-Crips Experimental Index; CCEI; Birtchnell, Evans and Kennard (1988))	Perceived stigma (Perceived stigma scale (created by authors))	Pearson's Correlation Stepwise multiple regression analysis	A significant positive correlation was found between neuroticism and perceived stigma and social support. Neuroticism did not remain a significant predictor of perceived stigma when entered into a multiple regression analysis (only social support and depression variables remained as significant predictors).
8 Standage & Fenton (1975) United Kingdom	Cross-sectional (Matched between groups subject design)	N= 37 (N=19 temporal lobe epilepsy N=15 generalised epilepsy N=3 non-temporal focal epilepsy) Outpatient clinics %female: 56 Mean Age: 36	Neuroticism, Extraversion (Eysenck Personality Inventory: EPI; Eysenck and Eysenck (1964))	Prevalence of mental illness (Present State Examination (PSE); eighth edition; Wing, Birley, Cooper, Graham, & Isaacs, 1967; Non-psychotic symptoms section only)	Participants were split into a high scoring PSE and low scoring PSE group. Comparisons between groups carried out (no statistical test stated)	Participants with higher levels of neuroticism had higher scores on the PSE (high current psychiatric morbidity).

9 Swinkels, Emde Boas, Kuyk, van Dyck, & Spinhoven (2006). The Netherlands	Cross-sectional	N= 131 (67 temporal lobe epilepsy (TLE), 64 extra-TLE) Inpatient and outpatient clinics %female: TLE: 61 Extra-TLE:36 Mean age: TLE: 44 Extra-TLE:37	Neuroticism, Extraversion, Openness Agreeableness, Conscientiousness (NEO-FFI)	Epilepsy related variables (age at onset, duration, seizure frequency, no. of AEDs)	Linear multiple regression and logistic regression.	A significant negative correlation was found between Neuroticism and duration of epilepsy. A significant negative correlation was found between agreeableness and number of AEDs. No other relationships were found between any of the 'Big 5' personality traits and age at onset, duration of epilepsy, duration of epilepsy, seizure frequency and number of AEDs.
10 Uijl et al. (2006) The Netherlands	Cross-sectional	N= 173 (any diagnosis of epilepsy; well controlled using AEDs). Recruited from seven hospitals. *Outpatient presumed due to well-controlled epilepsy.* %female: 50 Mean age: 48	Neuroticism (Symptom checklist; SCL-90: Dutch version; Arrindell and Ettema (1986))	Subjective complaints within 10 categories: general central nervous system (CNS) complaints, behaviour (irritability) depression, cognitive function, motor problems and co-ordination, visual complaints, headache, cosmetic and dermatological complaints, gastrointestinal complaints and sexuality and menses. *A total subjective complaints score was computed for main analysis.* (SIDAED- 46-item subjective complaints questionnaire created by authors)	Correlations Linear regression modelling	A significant positive correlation was found between neuroticism and total weighted subjective complaint score. In multivariable linear regression modelling neuroticism score was the primary predictor of subjective complaints (other predictors included QoL, AED variables, sex, polytherapy and time since last seizure).

11 Vermeulen, Aldenkamp, & Alpherts (1993) The Netherlands	Cross-sectional	N=102 (31 neurosurgical candidates with medication resistant epilepsy; n=71 general epilepsy participants) Outpatient clinics %female: Neurosurgery: 36 General: 47 Mean age: Neurosurgery: 33.5 General: 39.9	Neuroticism (ABV-Amsterdamse Biografische Vragenlijst)	Subjective memory complaints (23 Questions form the inventory of memory experiences (IME; Hermann & Neisser, 1978) and cognitive failure questionnaire (CFQ; Broadbent, Cooper, Fitzgerald, & Parkes, 1982) were used and factor analysed to produce 5 factors.)	Pearson's correlation	When analysed separately, neuroticism did not correlate with subjective memory complaints in the neurosurgical or general epilepsy group. When the two epilepsy groups were pooled together, a strong positive correlation was found between neuroticism and rote memory* and a moderate positive correlation was found between neuroticism and overall complaint score. **rote memory included remembering telephone numbers, directions, addresses and names of people met on social occasions* .
12 Zimmerman & Enderman (2008) Germany	Cross- sectional *Self-reported and carer-reported HRQoL data collected. This review takes information from self-reported HRQoL data only.*	N=36 (Young adults with epilepsy and mild intellectual disabilities) Short-term residential rehabilitation centre %female:39 Mean age: 26	Neuroticism, Extraversion (NEO-FFI)	Health related QoL (HRQoL) (QoL in epilepsy scale, QOLIE-31) Anxiety and depression (Hospital Anxiety and Depression Scale; HADS).	Spearman's and Pearson's correlation	Significant positive correlations were found between neuroticism and anxiety and depression (the higher the neuroticism score the higher the anxiety and depression score) Significant negative correlations were found been neuroticism and total QOLIE-31 score. Significant negative correlations were also found between neuroticism and the QOLIE-31 subscales of; seizure worry; overall QOL; emotional well-being, energy/fatigue; medication effects; and social functioning. * Significant negative correlations were found between extraversion and anxiety and depression (the higher the extraversion score the lower the anxiety and depression score)

						Significant positive correlations were found between extraversion and total QOLIE-31 score. Significant positive correlations were also found between extraversion and the QOLIE-31 subscales of; overall QOL; energy/fatigue; and social functioning.
13 Walsh, Thomas, Church, Rees, Marson, & Baker (2014). United Kingdom	Cross-sectional	N=60 (drug- refractory juvenile myoclonic epilepsy) Outpatient epilepsy clinics %female: 75 Median age: 31	Neuroticism, Extraversion (Eysenck Personality Questionnaire- Brief Version; EPQ-BV; Sato (2005))	Anxiety and depression (HADS) Concentration and motor difficulties (Aldenkamp-Baker Neuropsychological Assessment Scale (ABNAS; Aldenkamp, van Meela, Baker, Brooks, & Hendriks, 2002). Impact of epilepsy on living (impact of epilepsy scales; IES; no reference given) Battery of psychometric tests to evaluate: Intellectual ability, language functioning, verbal and non-verbal memory and executive functioning. *Full details given in subsequent paper (Thomas et al., 2014)*	T-tests Mann- Whitney U test Pearson's correlations Hierarchical Regression analysis	A significant relationship was found between higher neuroticism scores and higher anxiety symptoms, concentration difficulties and motor difficulties. (no significant relationship were found with extraversion). Individuals with high neuroticism scores performed worse on overall cognitive and executive functioning tests, compared with those with lower neuroticism scores. No difference was found in impact of epilepsy on the lives of those who reported high or low neuroticism and extraversion. All groups rated their epilepsy as having a moderate impact on their lives.

14 Zhu, Jin, Xie, & Xiao (1998). China	Cross – sectional	N=117 (39 generalised epilepsy, 63 partial epilepsy, 15 inconclusive) Recruited from hospital base (inpatient/outpatient not stated) %female: 22 Mean age: 28.5	Neuroticism, Extraversion (Eysenck Personality Questionnaire; EPQ; Gong (1986))	General well-being (General Well-being Schedule; Fan, 1993) Support: Subjective support, objective support and utilization of support (The social support scale; Xiao, 1993) Negative Life Events: family-related, work-related and social –related (Life Events Scale; Zhang & Yang, 1993) Manic behaviour (M), competitiveness and hostility (CH), tendency to lie (L). (Behaviour Pattern Scale; Zhang, 1993)	Pearson's correlation. Step-wise regression analysis	Extraversion scores were positively associated with general well-being, objective support, and utilization of that support. Extraversion scores were negatively associated with negative life events related to family and work. Neuroticism scores were positively associated with M, CH, negative life events in the family and work-related problems. Neuroticism scores were negatively associated with general well-being. In a step-wise regression analysis with general well-being as the dependant variable, neuroticism and extraversion were shown to be significant predictors; however the percentage of variance was not stated.
15 Canizares, Torres, Boget, Rumia, Elices, & Arroyo (2000) Spain	Pre-post-epilepsy surgery study	N=33 (partial epilepsy; temporal or mesiotemporal) Recruited from individuals undergoing pre-epilepsy surgery assessment (inpatient/outpatient not stated). %female: 55 Mean age: 31	Neuroticism (EPQ-A, Spanish version; Eysenck and Eysenck (1989))	Subjective cognitive functioning (QOLIE-31; cognitive functioning scale)	Pearson's correlation Multiple linear regression analysis	A relationship was found between higher neuroticism scores and lower subjective cognitive functioning scores post-surgery. A trend was also found in this direction pre-surgery, however this was not statistically significant. No other variable was found to predict subjective cognitive functioning post-surgery, other than neuroticism (i.e. seizure control or objective memory functioning)

16 Huang, Hayman-Abello, Hayman-Abello, Derry, & McLachlan (2014) Canada	Pre- post-epilepsy surgery study	N=48 (focal temporal epilepsy) Recruited form inpatient epilepsy monitoring unit whilst undergoing assessment for neurosurgery. %female: 52 Mean age: 39	Neuroticism (Positive and Negative Effect Scale; PANAS; Watson, Clark and Tellegan (1988))	Subjective memory (frequency of forgetting 10 scale; FOF-10; Zelinski & Gilewski, 2004)	Pearson's Correlation	No correlation was found between subjective memory and neuroticism before or after surgery.
17 Wilson, Wrench, McIntosh, Bladin, & Berkovic (2009) Australia	Participants recruited to take part in 2 year prospective longitudinal study (pre- and post-epilepsy surgery). *This paper presents cross sectional data from pre-surgery time point.*	N=57 (focal epilepsy) Recruited from inpatient assessment for neurosurgery clinics. % female:47 Mean age: 35	Neuroticism, Extraversion (EPQ-R short form, Barret & Eyesenck, 1992)	Depression (BDI-II; Beck, Steer, & Brown, 1996) Anxiety (State Trait Anxiety Inventory; Speilberger, 1983) Adjustment to epilepsy and psychosocial functioning (Austin CEP interview; Wilson, Bladin, & Saling, 2004)	T-tests Analysis of Variance (ANOVAs) Multivariate analysis of variance (MANOVAs) Chi-square analysis	High neuroticism and low extraversion was related to high depression ratings. Individuals with high neuroticism reported grater levels of anxiety and greater difficulties with family dynamics, compared to those with low neuroticism.

18 Wilson, Wrench, McIntosh, Bladin, & Berkovic (2010) Australia	Participants recruited to take part in 2 year prospective longitudinal study (pre- and post-epilepsy surgery). *This paper presents data from post-surgery time points (1- 3- and 12-months after surgery)*	N=57 (focal epilepsy) Recruited from inpatient assessment for neurosurgery clinics. % female:47 Mean age: 35	Neuroticism, Extraversion (EPQ-R short form, Barret and Eyesenck, 1992)	Depression (BDI-II) Anxiety (State Trait Anxiety Inventory) HRQoL (HRQoL Epilepsy surgery inventory-55; Rand, 1990) Psychological experience of learning to live without epilepsy; "the burden of normality" incl. family dynamics and social functioning. (Austin CEP Interview) Perceived changes in self-identity (Bespoke Likert scales)	Analysis of Variance (ANOVAs) Chi-square analysis	Individuals with high neuroticism and low extraversion were predisposed to greater depression levels after surgery. No significant effects of personality on HRQoL, anxiety or perceived self-change after surgery. Most (>70%) of patients with high neuroticism reported disrupted family dynamics, difficulties adjusting to seizure freedom and difficulties relating to the "burden of normality" after surgery. High extraversion was associated with disrupted family dynamics after surgery.
19 Witt, Hollman, & Helmstaedter (2008) Germany	Pre- post-epilepsy surgery study	N=151 (N=125 temporal, N=26 extratemporal) Recruited from individuals undergoing pre-epilepsy surgery assessment (inpatient/outpatient not stated). % female: 51 Mean age: 37	Neuroticism, Extraversion (Fragebogen zur Personlichkeit bei zerebralen Erkankungen; FPZ, Helmstaedter & Gleinbner, 1999)	Seizure freedom (amount of seizures)/control Depression (BDI-II)	Pearson's correlation. Paired t-tests.	No relationship between extraversion and depression was found pre-surgery. Post-surgery, seizure freedom was associated with a significant change in neuroticism i.e. for those who achieved seizure freedom, neuroticism scores significantly decreased from pre- to post-surgery.

*Neuroticism analysis was replicated in paper 1) Endermann & Zimmerman (2009); however more detail was given in this 2008 paper re. subscales so this data was included in the extraction table twice. Caution will therefore be applied to data synthesis.

Table 4
Quality Appraisal

	Paper	Downs and Black (1998) Checklist Question																											Total Quality Score (%*)
		1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**17**	**18**	**19**	**20**	**21**	**22**	**23**	**24**	**25**	**26**	**27**	
1	Endermann & Zimmerman (2009)	1	1	1	X	2	1	1	X	X	0	1	1	0	X	X	1	X	1	X	1	X	X	X	X	1	X	0	**81%**
2	Helmstaedter & Witt (2012)	1	1	1	X	2	1	0	X	X	0	1	0	0	X	X	1	X	1	X	1	X	X	X	X	1	X	0	**69%**
3	Hendricks et al. (2002)	1	1	1	X	1	1	1	X	X	1	0	0	1	X	X	1	X	1	X	1	X	X	X	X	1	X	0	**75%**
4	Lacey et al. (2016)	1	1	1	X	1	1	1	X	X	1	1	1	1	X	X	1	X	1	X	1	X	X	X	X	1	X	0	**88%**
5	Margolis et al. (2018)	1	1	1	X	2	1	1	X	X	1	1	0	1	X	X	1	X	1	X	1	X	X	X	X	1	X	1	**81%**
6	Molleken et al. (2010)	1	1	1	X	1	1	1	X	X	1	1	1	1	X	X	1	X	1	X	1	X	X	X	X	1	X	0	**88%**
7	Olley (2001)	1	1	1	X	1	1	1	X	X	1	1	1	1	X	X	1	X	1	X	1	X	X	X	X	0	X	1	**88%**
8	Standage & Fenton (1975)	1	1	1	X	1	1	0	X	X	0	0	0	1	X	X	1	X	0	X	1	X	X	X	X	0	X	0	**50%**
9	Swinkles et al. (2006)	1	1	1	X	1	1	1	X	X	0	1	0	1	X	X	1	X	1	X	1	X	X	X	X	1	X	0	**75%**

10	Uijl et al. (2006)	1	1	1	X	1	1	1	X	X	1	1	0	1	X	X	1	X	1	X	1	X	X	X	X	1	X	0	**81%**
11	Vermeulen et al. (1993)	0	1	1	X	1	1	1	X	X	0	0	0	0	X	X	1	X	1	X	1	X	X	X	X	1	X	0	**56%**
12	Zimmerman & Endermann (2008)	1	1	1	X	1	1	1	X	X	0	1	1	0	X	X	1	X	1	X	1	X	X	X	X	0	X	1	**75%**
13	Walsh et al. (2014)	1	1	1	X	1	1	1	X	X	1	0	0	1	X	X	1	X	1	X	1	X	X	X	X	0	X	0	**69%**
14	Zhu et al. (1998)	0	1	1	X	1	1	1	X	X	0	0	0	0	X	X	1	X	1	X	1	X	X	X	X	0	X	0	**50%**
15	Canizares et al. (2010)	1	1	1	X	1	1	1	X	1	1	0	0	1	X	X	1	1	1	1	1	X	X	X	X	1	1	0	**80%**
16	Huang et al. (2014)	1	1	1	X	1	1	1	X	1	1	0	0	1	X	X	1	1	1	1	1	X	X	X	X	1	1	0	**80%**
17	Wilson et al. (2009)	1	1	1	X	1	1	1	X	X	1	0	0	1	X	X	1	X	1	X	1	X	X	X	X	0	X	0	**69%**
18	Wilson et al. (2010)	1	1	0*	X	0	1	1	X	0	0	0	0	0	X	X	1	1	1	1	1	X	X	X	X	0	0	0	**45%***
19	Witt et al. (2008)	1	1	1	X	1	1	1	X	0	1	0	0	1	X	X	1	1	1	1	1	X	X	X	X	1	0	0	**70%**

Notes: X = not applicable; % = total quality percentage calculated out of applicable items
* This paper followed on from the study described in paper 16, therefore the methodology and participant characteristics are not described in detail in this subsequent paper.

Main findings

Big '5' Personality Factors Studied and Measures Used

Every study included in this review measured neuroticism with seven studies investigating neuroticism as the sole 'Big 5' personality factor. Neuroticism measures used in studies that investigated neuroticism as the sole personality trait included the Amsterdamse Biografische Vragenlijst (ABV), the International Personality Item Pool (IPIP-N): Neuroticism Scale, the Crown-Crips Experimental Index (CCEI), the Symptom Checklist (SCL-90; Dutch version) the Eyesenck Personality Questionairre (EPQ-A; Spanish version) and the Positive and Negative Effect Scale; PANAS. Only two studies investigated all 'Big 5' personality traits (Molleken at al. 2010; Swinkles et al., 2006). Both of these studies measured the 'Big 5' by using the NEO five-factor inventory (NEO-FFI). The remaining seven studies investigated neuroticism and extraversion, two of which also used the NEO-FFI to measure these traits. Other measures used to investigate both neuroticism and extraversion included the Eysenck Personality Questionnaire- Brief Version (EPQ-BV) and the Eysenck Personality Questionairre- Revised Short Form (EPQ-R-SF). Helmstaedter and Witt (2012) used the Fragebogen zur Personlichkeit bei Zerebralen Erkankungen (FPZ) to measure both neuroticism and introversion (the opposite pole of extraversion; Thompson, 2008).

CCs of 'Big 5' Personality Traits and Measures Used

The CCs of the 'Big 5' personality factors included in the studies fell into six categories: (1) mental health, (2) QoL, (3) adjustment and changes to identity, (4) subjective complaints, (5) objective cognitive performance, and (6) seizure variables. Individual items that were included in these categories, along with the measures used to investigate them, are presented below.

Mental health: Anxiety and depression. The most common CC used in the reviewed studies was mental health. Eight papers included variables relating to mental health (primarily anxiety and depression) as a CC of personality within their study. Five papers (produced from three studies) reported both anxiety and depression as CCs (Endermann & Zimmerman, 2009; Zimmerman & Endermann, 2008; Walsh et al., 2014; Wilson et al; 2009; Wilson et al, 2010) with three papers (two studies) using the Hospital Anxiety and Depression Scale (HADS) to measure both of these variables (Endermann & Zimmerman, 2009; Zimmerman & Endermann, 2008; Walsh et al., 2014). Wilson et al. (2009; 2010) also included both anxiety and depression as CCs, however, they used separate scales to measure each of these, namely the State Trait Anxiety Inventory and the Beck Depression Inventory-II (BDI-II). Helmstaedter and Witt (2012) and Witt et al. (2008) also used the BDI-II in their studies to measure depression as the only CC relating to mental health. Lacey et al. (2016) also included depression only, and used the Centre for Epidemiologic Studies Depression Scale (CES-D) to measure this.

Quality of life. The second most common CC included was QoL. Seven papers (produced from six studies) included QoL (and related variables) as a CC within their study (Endermann & Zimmerman, 2009; Margolis et al., 2018; Molleken et al., 2010; Zimmerman & Endermann, 2008; Walsh et al., 2014; Canizares et al., 2000; Wilson et al., 2010). Endermann and Zimmerman, (2009) and Zimmerman and Endermann (2008) assessed overall QoL using the QoL in Epilepsy Scale (QOLIE-31), whereas other studies used subscales of this overall scale to measure certain aspects of QoL. For example Canizares et al. (2000) used The Cognitive Functioning Scale of the QOLIE-31 to measure subjective cognitive appraisal. Margolis et al. (2018) used two subscales of the full 89-item QOLIE-89 scale (social isolation and work/driving/social functioning subscale) to focus their assessment on social aspects of QoL. They also investigated if

stigma was a mediator of QoL and used the Epilepsy Stigma Scale (ESS) to measure this. Olley et al. (2001) focussed solely on stigma as their dependant outcome variable, using a perceived stigma scale created by the authors.

Molleken et al. (2010) focussed upon sexual QoL (SQoL) and administrated the Derogatis Interview for Sexual Function-Self Report Inventory (DISF-SR) to measure this. This study also used the Life Satisfaction Questionnaire (LSQ) to measure general life satisfaction; a potential confounding variable to SQoL. Wilson et al. (2010) used a measure of QoL relevant to epilepsy surgery, namely the Epilepsy Surgery Inventory-55 (ESI-55). Walsh et al. (2014) utilised the Impact of Epilepsy Scales to measure the impact of epilepsy on everyday living, particularly how disruptive the condition has been to the participant's life.

Adjustment and changes to identity. Two papers (produced from one study, Wilson et al. 2009; 2010) included adjustment as a CC, investigating both adjustment to living with epilepsy and adjustment to life after epilepsy surgery at the relevant time points. Wilson et al. (2009; 2010) used the Austin CEP Interview to investigate adjustment to epilepsy and psychosocial functioning before surgery, and the psychological experience of learning to live without epilepsy after epilepsy surgery. At post-surgery Wilson et al. (2010) also explored perceived changes in self-identify by using bespoke Likert scales developed by the authors.

Subjective complaints. Four studies included some form of measuring subjective complaints from participants as a CC to personality. As previously mentioned, Canizares et al. (2000) used the cognitive functioning subscale of the QOLIE-31 to measure subjective cognitive functioning. Two studies investigated subjective memory complaints. Hendricks et al. (2002) measured subjective memory complaints using the

Geheugen Klachten Lijst voor Epilepsie (GKLE) whereas Huang et al. (2014) used The Frequency of Forgetting 10 scale (FOF-10). Uijl et al. (2006) computed a total subjective complaints score from the (SIDAED). This self-report questionnaire measured subjective complaints within 10 categories including general central nervous system (CNS) complaints, behaviour (irritability) depression, cognitive function, motor problems and co-ordination, visual complaints, headache, cosmetic and dermatological complaints, gastrointestinal complaints and sexuality and menses.

Objective cognitive performance. Helmstaeder & Witt (2012) and Walsh et al. (2014) both include measures of objective cognitive functioning as a CC in their studies. Both of these papers reference other publications to give full details of the battery of psychometric tests administered (Clusmann et al., 2002 and Thomas et al., 2014 respectively). Helmstaeder & Witt (2012) investigated the cognitive facets of attention, language, memory, and visuoconstruction whereas Walsh et al. (2014) evaluated intellectual ability, language functioning, verbal and non-verbal memory and executive functioning. Walsh et al. (2014) also administrated the Aldenkamp-Baker Neuropsychological Assessment Scale (ABNAS) to measure concentration and motor difficulties.

Seizure variables. Two studies used seizure-related variables as a CC of personality. Swinkles et al. (2006) measured a variety of epilepsy related variables including duration and frequency of seizures and number of antiepileptic drugs (AEDs) prescribed. Witt et al. (2008) investigated seizure control (presence vs. absence of seizures) a year after surgery.

Relationship between Personality Factors and CCs

Mental Health

Neuroticism and anxiety.

The relationship between neuroticism and anxiety was investigated in five papers. (Endermann & Zimmerman, 2009; Zimmerman & Endermann, 2008; Walsh et al., 2014; Wilson et al.; 2009; Wilson et al., 2010). A positive relationship between neuroticism and anxiety was found in four out of five papers. Zimmerman and Endermann (2008) and Endermann and Zimmerman (2009) reported a positive correlation between neuroticism scores and anxiety scores ($r = .69$, $p \leq .01$). Endermann and Zimmerman (2009) reported that neuroticism remained a significant predictor for anxiety when entered into a stepwise multiple regression analysis, explaining 46% of the variance. When age of epilepsy onset was added to the regression analysis, neuroticism improved variance explanation by 6%. Furthermore, Walsh et al. (2014) reported that individuals with higher neuroticism scores reported higher anxiety symptoms compared with those with lower neuroticism scores ($d = 1.57$, $p = .001$) . Wilson et al. (2009) reported that individuals with high neuroticism reported greater levels of anxiety ($M = 43.48$) compared to those with low neuroticism ($M = 35.74$, $p \leq .05$) pre-epilepsy surgery. However, Wilson et al. (2010) found no significant effects of neuroticism on anxiety post- epilepsy surgery.

Neuroticism and depression

The relationship between neuroticism and depression was investigated in six papers (Endermann & Zimmerman, 2009; Zimmerman & Endermann, 2008; Walsh et al., 2014; Helmstaedter & Witt, 2012; Witt et al., 2008; Lacey et al., 2016). Four of these papers reported a positive relationship between neuroticism and depression.

Zimmerman and Endermann (2008) and Endermann and Zimmerman (2009) reported a positive correlation between neuroticism scores and depression scores (r = .72, $p \leq$ .001). Endermann and Zimmerman (2009) reported that neuroticism remained a significant predictor for depression when entered into a stepwise multiple regression analysis, explaining 51% of the variance. When gender was added to the regression analysis, neuroticism improved variance explanation by 10%, with men being at greater risk of depression. Helmstaeder and Witt (2012) reported that depression scores showed high, positive correlations to neuroticism scores (r = .58), however no significance value was given. Lacey et al. (2016) found a strong, positive correlation between depressive symptoms and neuroticism (r_s = .78, $p \leq .001$). When factors were entered into a linear regression model, neuroticism was found to be the primary predictor for depression (accounting for 52% of variance). Other factors included in this model were physical functioning, social support, stressful life events and past history of depression.

Extraversion and anxiety

The relationship between extraversion and anxiety was investigated in two papers; one reported a significant relationship and one did not. Zimmerman and Endermann (2008) found a significant negative correlation between extraversion and anxiety scores (r = -.35, $p \leq .05$). However, Walsh et al. (2014) found no significant differences between those who reported high or low extraversion scores and their anxiety levels.

Extraversion and depression

The relationship between extraversion and depression was investigated in four papers. 50% of these papers reported a significant relationship between extraversion and depression. Zimmerman and Endermann (2008) found a significant negative correlation

between extraversion and depression scores (r = -.75, $p \leq .001$). Helmstaeder and Witt (2012) also reported that depression scores show minor correlation to the introversion scores (r = .27), however no significance value was given. Witt et al. (2008) reported no relationship between extraversion and depression pre- epilepsy surgery and Walsh et al. (2014) found no significant differences between those who reported high or low extraversion scores and their depression levels.

Extraversion and neuroticism

Wilson et al. (2009; 2010) evaluated the relationship between neuroticism, extraversion and mental health (depression and anxiety). Wilson et al. (2009) reported that individuals with high neuroticism reported greater levels of depression and anxiety compared to those with low neuroticism pre- epilepsy surgery. This was particularly pertinent when high neuroticism was accompanied by lower extraversion. This relationship between neuroticism, extraversion and depression was again found by Wilson et al. (2010) post- epilepsy surgery. However, Wilson et al. (2010) found no significant effects of personality (extraversion or neuroticism) on anxiety after epilepsy surgery.

Quality of Life

Neuroticism

The relationship between neuroticism and QoL was investigated in seven papers. (Zimmerman & Endermann, 2008; Endermann & Zimmerman, 2009; Margolis et al., 2018, Molleken et al., 2010; Olley, 2001; Walsh et al., 2014; Wilson et al., 2010). Five of these reported a negative relationship between neuroticism and QoL. Zimmerman and Endermann (2008) and Endermann and Zimmerman (2009) reported a negative correlation between neuroticism scores and HRQoL (r = -.75, $p \leq .001$). When

investigating the facets of QoL in more detail, Endermann and Zimmerman (2008) reported negative correlations between neuroticism and the QOLIE-31 subscales of seizure worry (r_s = -.39, $p \leq .01$); overall QoL (r_s = -.64, $p \leq .001$); emotional well-being (r_s = -.62, $p \leq .001$); energy/fatigue (r_s = -.65, $p \leq .001$); medication effects (r_s= -.62, $p \leq .001$); and social functioning (r = -.61, $p \leq .001$). The only QOLIE-31 subscale that neuroticism did not show a significant relationship with was cognitive functioning. Furthermore, Zimmerman and Endermann (2008) and Endermann and Zimmerman (2009) reported that neuroticism remained a significant predictor for HRQoL when entered into a stepwise multiple regression analysis, explaining 54% of the variance. When age of epilepsy onset was added to the regression analysis, neuroticism improved variance explanation by 7%. Simple slope analysis (reported in Zimmerman & Endermann, 2008) revealed the regression of QoL on age of onset was strongest for low levels of neuroticism. In participants who scored low in neuroticism, QoL was better with epilepsy onset during childhood (under 11 years of age) compared to adolescence. However, this difference did not occur in participants who reported high levels of neuroticism. They had comparatively low QoL levels independent of age of epilepsy onset.

Olley (2001) reported a significant positive correlation between neuroticism and perceived stigma *(r* =. 35, p = .005). However, neuroticism did not remain a significant predictor of perceived stigma when entered into a multiple regression analysis (only social support and depression variables remained as significant predictors of perceived stigma). Molleken et al. (2010) also found that life satisfaction correlated negatively with neuroticism (r = -.58, p <. 001). In addition, Margolis et al. (2018) found that higher levels of neuroticism were associated with greater perceived stigma. Stigma, in turn, was significantly and independently associated with poorer social wellbeing. They therefore conclude that neuroticism is indirectly associated with social well-being

though its associations with perceived stigma. However, Walsh et al. (2014) found no difference between impact of epilepsy on the lives of those who reported high or low neuroticism. Both groups rated their epilepsy as having a moderate impact on their lives. Wilson et al. (2010) also found no significant effects of neuroticism on HRQoL after surgery.

Extraversion, agreeableness, conscientiousness and openness.

The relationship between extraversion and QoL was investigated in five papers, three of which reported a positive relationship. Molleken et al. (2010) also investigated into the relationship between QoL and agreeableness, conscientiousness and openness. Molleken et al. (2010) reported that lower extraversion (and female sex) were factors associated with decreased SQoL (explaining 22%-29% of the overall variance of SQoL depending on if raw or adjusted scores were entered). They also found that life satisfaction correlated positively with extraversion ($r = .57$, $p < .001$), agreeableness ($r = .44$, $p = .04$) and conscientiousness ($r = .40$, $p = .04$). No significant relationship was found for life satisfaction and openness. Margolis et al. (2018) found that lower levels of extraversion were significantly associated with greater perceived stigma. Stigma, in turn, was significantly and independently associated with poorer social wellbeing. They therefore conclude that extraversion is indirectly associated with social well-being though its association with perceived stigma.

Zimmerman and Endermann (2008) reported significant positive correlations between extraversion and QoL ($r = .38$, $p \leq .01$). When looking into QoL in more detail, they reported significant positive correlations between extraversion and the QOLIE-31 subscales of; overall QOL ($r_s = .47$, $p \leq .01$); energy/fatigue ($r_s = .43$, $p \leq .01$); and social functioning ($r_s = .34$, $p \leq .05$). However, Wilson et al. (2010) found no significant effects of extraversion on HRQoL after surgery. Walsh et al. (2014) also

found no difference was found in impact of epilepsy on the lives of those who reported high or low extraversion. Both groups rated their epilepsy as having a moderate impact on their lives.

Adjustment and Changes to Identity

Two papers (Wilson et al., 2009; 2010), derived from one study investigated the relationship between neuroticism and extraversion on adjustment and changes to identity pre- and post-epilepsy surgery. They reported mixed results, stating that individuals with high neuroticism reported greater difficulties with family dynamics before and after surgery, compared to those with low neuroticism. This was particularly pertinent when high neuroticism was accompanied by lower extraversion. After surgery individuals with high neuroticism scores were also more likely to report psychological features of the burden of normality and difficulties adjusting to seizure freedom. Wilson et al. (2010) found no significant effects of personality (extraversion or neuroticism) on perceived self-change after epilepsy surgery, however they did find that over 70% of individuals with high neuroticism levels reported difficulties in adjusting to seizure freedom after epilepsy surgery.

Subjective Complaints

Of the four studies investigating subjective relationships and personality, three reported to find at least one significant relationship. Hendricks et al. (2002) report significant weak positive correlations between neuroticism and overall subjective memory complaints ($r = .14$, $p \leq .05$), and neuroticism and subjective memory complaints for semantic structures ($r = .30$, $p \leq .05$). However, when entered into a multiple regression analysis the contribution of neuroticism to overall variance of total memory score was modest (11%). Uijl et al. (2006) found a significant positive

correlation between neuroticism and total weighted subjective complaint score (r = .32, p < .01). The subjective complaints investigated included behaviour (irritability), depression, cognitive function, motor problems and co-ordination, general central nervous system (CNS) complaints, visual complaints, headache, cosmetic and dermatological complaints, gastrointestinal complaints and sexuality and menses. In multivariable linear regression modelling neuroticism score was the primary predictor of overall subjective complaints (variance accounted for by neuroticism alone was not reported). Other predictors included QoL, AED variables, sex, polytherapy, and time since last seizure.

Canizares et al. (2000) reported a negative relationship neuroticism and subjective cognitive functioning scores post- surgery (r = -.55, p = .001). A trend was also found in this direction pre-surgery, however this was not statistically significant. When entered into a multiple regression analysis no variable other than neuroticism (i.e. seizure control or objective memory functioning) predicted post-surgery subjective cognitive functioning. Neuroticism accounted for 35% of the overall variance in subjective cognitive functioning. However, Huang et al. (2014) reported no significant correlation between subjective memory and neuroticism before or after surgery. Walsh et al. (2014) reported that individuals with higher neuroticism scores reported higher concentration and motor difficulties compared with those with lower neuroticism scores (d = 1.18, p = .007; d = 1.41, p = .006 respectively). No difference was found in concentration or motor complaints when comparing those with high and low levels of extraversion.

Objective Cognitive Performance

Both papers investigating the relationship between personality and objective cognitive performance reported significant relationships. Helmstaedter and Witt (2012) found a positive correlation between introversion and better cognitive status scores, measured via a battery of psychometric tests, however do not provide a significance value. Walsh et al. (2014) reported that individuals with high neuroticism scores performed significantly worse on overall cognitive and executive functioning tests, compared with those with lower neuroticism scores. They also reported a trend that those with low extraversion scored lower on cognitive tests (namely the Boston Naming Tests; Kaplan, Goodglass, & Weintraub, 1983) than those with high extraversion.

Seizure Variables

Both papers investigating the relationship between personality and seizure variables reported significant relationships. Swinkles et al. (2006) reported a significant negative correlation between neuroticism and duration of epilepsy and a significant negative correlation between agreeableness and number of AEDs (correlation co-efficient unavailable). No other relationships were found between any of the 'Big 5' personality traits and age at onset, duration of epilepsy, seizure frequency and number of AEDs. Witt et al. (2008) reported that post-surgical seizure freedom was associated with a significant change in neuroticism i.e. for those who achieved seizure freedom, neuroticism scores significantly decreased from pre- to post- surgery ($t = 2.83$, $p = .006$).

Discussion

The aim of this review was to collate and critically evaluate research investigating the relationship between the 'Big 5' personality traits and clinical correlates (CCs; indicators of adjustment) in people with epilepsy. As this review is the first to collate literature published in this area, focus was placed on the identification of personality factors and CCs included in relevant studies and how these were measured. The review showed that neuroticism was the most commonly included 'Big 5' personality trait, followed by extraversion, most commonly measured by the NEO-FFI and EPQ. These personality traits were correlated with items that feed into six main categories: (1) mental health, (2) QoL, (3) adjustment and changes to identity, (4) subjective complaints, (5) objective cognitive performance, (6) seizure variables. Findings suggest higher neuroticism levels were associated with poorer mental health, poorer quality or life, poorer adjustment and higher subjective complaints in epilepsy populations. Higher levels of extraversion were shown to be associated with a higher QoL.

Personality Traits and CCs, and How They Are Measured.

Neuroticism was the most commonly included 'Big 5' personality trait, followed by extraversion. Only two studies included all 'Big 5' personality traits. The NEO-FFI and EPQ were the most common measures used for investigating personality traits. Mental health was the most commonly included CC; namely anxiety and depression. The most common measures used to assess anxiety and depression were the HADS, BDI-II and State Trait Anxiety Inventory. QoL was the second most common CC and studies included this correlate in different ways including overall health related QoL and specific subsets of QoL e.g. sexual QoL. Health related QoL was most commonly

measured using the QOLIE, and some studies used subscales of this to measure specific aspects e.g. social isolation. Adjustment and changes to identity were measured pre- and post-epilepsy surgery using the Austin CEP interview and bespoke Likert scales. Four studies investigated subjective complaints covering a wide range of correlates including memory complaints and cognitive functioning complaints. Each study used a different measure. Two studies used batteries of psychometric tests to measure objective cognitive performance. Correlates classed as seizure variables included duration and frequency of seizures, number of AEDs prescribed and seizure control.

Relationship Between Personality Traits and CCs.

Personality and mental health. Findings suggested that neuroticism is associated with high anxiety and depression in people with epilepsy. This mirrors findings from the general population and psychiatric populations, which indicate that neuroticism is a strong risk factor for diagnosed mental illnesses (Neeleman, Bijl, & Ormel, 2007) and is a potential general underlying vulnerability factor for psychopathology (Khan, Jacobson, Gerdner, Prescott, & Kindler, 2005), particularly depression (Kendler, Gatz, Gardner, & Pederson, 2006). Research from other seizure disorders and the general population has shown that high neuroticism scores predict poor outcomes in depression (Reuber et al., 2003; Kendler, Kuhn, & Prescott, 2004). Therefore the association between neuroticism and depression may not be specific for individuals with epilepsy, and may better reflect what one might expect in the general population. However, some studies suggest the presence of depression can lead to erroneous self-reporting of pre-morbid personality, particularly neuroticism (Costa, Bagby, Herbst, & McCrae, 2005). Sirois (2015) reported that neuroticism predicts low self-rated, and future self-rated health in chronic illness samples. Regardless of causality, both of these proposals may

limit the reliability and validity of self-reported associations between personality and mental health.

Findings relating to extraversion, anxiety and depression were inconclusive. This mirrors findings into the investigation between extraversion and mental health diagnoses in the general and psychiatric population, where extraversion is sometimes found to be associated with anxiety and depression, and sometimes not (Khan et al., 2005). Khan et al. (2005) also found extraversion to be negligible when investigating co-morbidity of mental health in the general population.

Personality and quality of life. Findings suggest that neuroticism is associated with poor QoL in people with epilepsy. Margolis et al. (2018) suggests that neuroticism is indirectly associated with social wellbeing through its associations with stigma and Olley (2001) reported associations between neuroticism and stigma and lower social support. However, it has been suggested that associations between personality and perceived stigma may be affected by variability in epilepsy-related stigma across cultures (Baker, Brooks, Buck, & Jacoby, 2000), and the findings of studies conducted in the USA or Nigeria may not be generalizable to all cultures. Nevertheless, these findings are from western and non-western cultures, suggesting stigma may be related more to the internal personality trait of neuroticism, rather than external cultural differences. This would be expected as the tendency of individuals with high neuroticism to experience negative affect has been shown to decrease QoL in the general population (Huang et al., 2017) and other chronic illnesses such as kidney disease (Ibrahim et al., 2015).

Findings suggested a positive relationship between extraversion and QoL. It is likely that those who are more extraverted would seek the company of others, therefore

obtaining more social support (Swickert, Rodentreter, Hittner, & Mushrush, 2002). This support could be used to help individuals cope with their condition, and in turn increase their QoL. Extraversion has also been shown to link with higher perceived health and QoL in the general population (Goodwine & Engstrom, 2002) and this may not be specific to the epilepsy population. Molleken et al. (2010) reported a positive association between life satisfaction and agreeableness, and a positive association between life satisfaction and conscientiousness. However, the dearth of research makes it difficult to draw conclusions relating to these personality traits.

Personality, adjustment and changes to identity. The findings regarding the relationship between personality, adjustment and changes in identity were mixed. High neuroticism paired with low extraversion was found to be associated with difficulty in family dynamics pre- and post- surgery. Neuroticism was also found to be associated with more difficulties in adjusting to seizure freedom and higher levels of burden of normality after surgery (Wilson et al., 2009; 2010). This corresponds with research conducted within the general population, which has shown an association between higher neuroticism and dysfunctional family dynamics, which, in turn are associated with poorer overall adjustment (Miller et al., 1992). Neuroticism has been associated with poor psychological adjustment to other chronic illness, including chronic kidney disease (Ibrahim et al., 2015) and multiple sclerosis (Ratsep et al., 2000).

In this review no significant effects of personality on perceived self-change after epilepsy surgery were reported. Research shows that neuroticism is most closely linked to personality change in adolescence, especially if this is also time of manifestation of regular seizures (Wilson, 2009). Therefore, as all participants were adults when they

underwent surgery, changes or adjustments in their identity may not have occurred due to an already established sense of self.

Personality and subjective complaints. Higher neuroticism was associated with higher subjective complaints and lower subjective cognitive functioning. This may reflect the general association between emotional liability (a characteristic of neuroticism) and a tendency to complain regarding one's health (Neitzert, Davis, & Kennedy, 1997; Watson, 1988). Therefore, this finding may not be specific to the epilepsy population. However, subjective complaints may be exacerbated in individuals with high neuroticism in the epilepsy population, due to the psychosocial consequences of having epilepsy, e.g. unemployment and stigma (Hendricks et al., 2002).

Personality and objective cognitive performance. The review indicates that individuals with high neuroticism scores perform worse overall in tests of cognitive and executive functioning. This supports de Araujo Filho et al.'s (2009) proposal that individuals with epilepsy and 'extreme personality traits' show difference in pre-frontal brain structure than those without 'extreme personality traits' and health controls. These differences in brain structure have been shown to be associated with a difference in neuropsychological and executive functioning (Swartz et al., 1996).

Personality and seizure variables. One study (Swinkles et al., 2006) showed a negative relationship between neuroticism and duration of epilepsy and a negative relationship between agreeableness and the number of AEDs. This dearth of research makes drawing conclusions difficult. Seizure freedom was also shown to be associated with a change in neuroticism levels pre- post- surgery, supporting the theory that

personality traits are reciprocally affected by changes in life circumstances i.e. seizure freedom (McCrae et al., 2000).

Limitations and Strengths

This review is the first investigate the relationship between the Big 5 personality traits and CCs in the epilepsy population. A systematic and comprehensive literature search was performed with a clearly focused research question defined a priori. Limitations to this review include the restriction of inclusion criteria to English language publications (especially as four potentially relevant articles were excluded due to this), absence of grey literature searches and hand searching through relevant journals. Furthermore, a second reviewer, who may have increased the reliability of the systematic literature search, was not used during article screening. Due to time and resource constraints an extensive search of all relevant healthcare databases could not be carried out; however the review included an adequate number of appropriately selected relevant databases in order to complete a comprehensive search of the literature.

The finding of this review in relation to the overall 'Big 5' personality factors are limited, as all of the studies included investigated neuroticism, with seven studies investigating neuroticism only. Therefore investigation of whether all of the CCs included in the review also relate to openness, agreeableness, conscientiousness and extraversion, and whether the 'Big 5' personality traits are associated with similar or different CCs (and therefore the investigation of possible trait association/overlap) was not possible. Furthermore it is important to acknowledge the psychometric properties of the measures used in the reviewed studies, as limitations of these could impact on the validity of the current review's conclusions. For example Crawford and Henry (2004) found that the PANAS does not possess factorial invariance across gender, and to date

this measure has not been assessed for factorial invariance across cultures or in clinical vs. non clinical samples. Furthermore some of the measures used to measure CCs in the included studies had been created by the authors, with no attempts to validate them with a clinical sample before use e.g. perceived stigma scale (Olley, 2007), changes in identity Likert scale (Wilson et al., 2010). Therefore the reliability and validity of these measures have not been evidenced and the current review's conclusions regarding associations between specific personality traits and CC should be treated with caution.

The use of a reliable, valid numerical rating scale to assess the quality of the papers included in the review (Down's & Black 1998) was a strength, as was the elimination of studies with poor quality ratings, in order to ensure that the conclusions reached are based on high quality evidence. However, the use of this tool is not without controversy as some recent research suggests domain based systems to be more effective at assessing overall quality of studies than numerical rating scales (O'Conner at al., 2015). Nevertheless, to increase reliability the use of an independent rater to assess methodological quality of the papers was as strength, as was the initial high inter-rater reliability (84% compatibility) between reviewers.

Future Directions

To enhance the meaningfulness and comparability of findings, epilepsy research would benefit from a consistent approach to the assessment of 'Big 5' personality traits and CCs. Studies incorporating all/ more of the 'big 5' personality traits, rather than just neuroticism, would further enhance understanding of the association between personality traits and adjustment in epilepsy. Future research should use the measures most frequently used in previous literature e.g. NEO-FFI, in order to allow for reliable comparisons between findings. As causal inferences cannot be drawn based on the

cross-sectional designs used in these studies, future research should employ longitudinal designs determine causality. The use of carer-report measures would allow further evaluation regarding the validity of self-report data, due to the potential effects of personality and current illness levels on self-report outcomes.

This review found associations between CCs and personality traits in the epilepsy population that were mirrored in the general population (e.g. neuroticism and depression). Including meta-analysis in future reviews to compare the magnitude of these associations found in the epilepsy and general population would provide further insights. Widening the scope of reviews to include personality traits other than the 'Big 5' (e.g. mid-level personality traits such as optimism, perfectionism and gratitude) would further develop understanding between personality and CCs. Review questions outside the scope of the current review which would be worth pursuing include the relationship between personality and adjustment in particular types of epilepsy as neuropsychological differences and difference in seizure control may influence one's personality and experience of epilepsy as a condition e.g. stigma, predictability of seizures. An exploration of age at onset of epilepsy, personality traits and adjustment is also suggested.

Clinical Implications

As neuroticism is potentially associated with poorer mental health and QoL in people with epilepsy, offering psychotherapy focussing on managing the characteristics of this personality trait (i.e. proneness to experiencing negative emotions and being easily overwhelmed by stress) may be beneficial e.g. mindfulness based cognitive therapy (Segal, Teasdale, & Williams, 2002) or dialectical behaviour therapy skills (Linehan, 2014). A routine personality screen for individuals at epilepsy diagnosis may

also be helpful to identity potential ‘at risk’ individuals, who may need further support to prevent or manage mental health difficulties such as anxiety and depression. These screenings may also be helpful for clinicians to be aware of individuals who may present with more subjective complaints (i.e. individuals who have higher neuroticism levels) in order to incorporate this into an overall formulation of difficulties. However, clinicians should be mindful that these subjective complaints may translate into objective cognitive difficulties, or be enmeshed with perceived stigma and/or lower QoL experienced by their clients.

Conclusion

In this review of the literature regarding personality and CCs in epilepsy populations, neuroticism was the most commonly included ‘Big 5’ personality trait, followed by extraversion. The NEO-FFI and EPQ were the most common measures used for investigating personality traits. These personality traits were correlated with items that feed into six main categories: (1) mental health, (2) QoL, (3) adjustment and changes to identity, (4) subjective complaints, (5) objective cognitive performance, (6) seizure variables. Not all categories included enough research to draw conclusions. However, findings suggest higher neuroticism levels were associated with poorer mental health, poorer QoL, poorer adjustment and higher subjective complaints in epilepsy populations. Furthermore, this review suggests that higher levels or extraversion may be associated with a higher QoL. This review cannot determine whether these associations are casual. Longitudinal research is needed to investigate these associations further, and comparing results to well matched control samples would provide the means to make more epilepsy-specific conclusions.

References

* Denotes studies included in this review

Aldenkamp, P., van Meela, H. F., Baker, G. A., Brooks, J., & Hendriks, M. (2002). The A–B neuropsychological assessment schedule (ABNAS): the relationship between patient-perceived drug related cognitive impairment and results of neuropsychological tests. *Seizure, 11,* 231-237. https://doi.org/10.1053/seiz.2002.0672

Aldwin, C. M., Spiro, A., Levenson, M. R., & Cupertino, A. P. (2001). Longitudinal findings from the normative aging study: III. Personality, individual health trajectories, and mortality. *Psychology and Aging, 16,* 450–564. doi: 10.1037/0882-7974.16.3.450

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., Text Revision). Washington, DC: American Psychiatric Association.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: American Psychiatric Assosciation.

Arrindell, W. A., & Ettma, J. H. M. (1986*). SCL:90 handleiding bij een multidimensionele psychopathologie-indicator.* Lisse: Swets & Zeitlinger.

Baker, G. A. (2002). The psychosocial burden of epilepsy. *Epilepsia, 43,* 26-30. doi: 10.1046/j.1528-1157.43.s.6.12.x

Baker, G. A., Brooks, J., Buck, D., & Jacoby, A. (2000). The stigma of epilepsy: a European perspective. *Epilepsia, 41,* 98-104. https://doi.org/10.1111/j.1528-1157.2000.tb01512.x

Barret, P. T., & Eysenck, S. B. G. (1992). Predicting EPQR full scale scores from the short form version. *Personality and Individual Differences, 13,* 851-853. doi: 10.1016/0191-8869(92) 90060-3.

Baxendale, S. (2014). *Epileptic personality: fact or fiction?* Presentation at the International League Against Epilepsy (ILAE) British Chapter Conference, Nottingham, UK.

Bear, D. M., & Fedio, P. (1977). Quantitative analysis of interictal behaviour in temporal lobe epilepsy. *Archives of Neurology, 34,* 454–467. doi:10.1001/archneur.1977.00500200014003

Beck, A., Steer, R. (1987). *Beck Depression Inventory Manual.* San Antonio, TX: Psychological Corporation.

Beck, A. T., Steer, R. A., & Brown, G. K. (1996). *Beck Depression Inventory: Second edition manual.* San Antonio, TX: Psychological Corp.

Benson, D. F. (1991). The Geschwind Syndrome. *Advances in Neurology, 55,* 411-421. Retrieved from http://europepmc.org/abstract/med/2003418

Birtchnell, J., Evans, C., & Kennard J. (1988). The total score of the Crown-Crisp Experiential Index: A useful and valid measure of psychoneurotic pathology. *British Journal of Medical Psychology, 61,* 255-66. https://doi.org/10.1111/j.2044-8341.1988.tb02787.x

Brickman, A. L., Yount, S. E., Blaney, N. T., Rothberg, S. T., & De-Nour, A. (1996). Personality traits and long-term health status. The influence of neuroticism and conscientiousness on renal deterioration in type-1 diabetes. *Psychosomatics, 37*, 459–468. doi: 10.1016/S0033-3182(96)71534-7

Broadbent, D. E., Cooper, P. F., Fitzgerald, P., & Parkes, K. R. (1982). The cognitive failures questionnaire (CFQ) and its correlates. *British Journal of Clinical Psychology, 21,* 1-16. https://doi.org/10.1111/j.2044-8260.1982.tb01421.x

Bruce, J. M., Hancock, L. M., Arnett, P., & Lynch, S. (2010). Treatment adherence in multiple sclerosis: association with emotional status, personality, and cognition. *Journal of Behavioural Medicine, 33,* 219–27. doi: 10.1007/s10865-010-9247-y

* Canizares, S., Torres, X., Boget, T., Rumia, J., Elices, E., & Arroyo, S. (2000). Does Neuroticism Influence Cognitive Self-Assessment After Epilepsy Surgery? *Epilepsia, 41*, 1303-1309. doi: 10.1111/j.1528-1157.2000.tb04609.x

Costa, P. T., Bagby, R. M., Herbst, J. H., & McCrae, R. (2005). Personality self-reports are concurrently reliable and valid during acute depressive episodes. *Journal of Affective Disorders, 89,* 45-55. https://doi.org/10.1016/j.jad.2005.06.010

Costa, P., & McCrae, R. (1989). *The NEO PI/FFR manual suppliment.* Odessa, Fl: Psychological Assessment Resources.

Costa, P., & McCrae, R. (1992). *Revised NEO Personality Inventory (NEO-PI-R) and NEO Five-Factor Inventory (NEO-FFI) manual.* Odessa, FL: Psychological Assessment Resources.

Christensen, A. J., Ehlers, S. L., Wiebe, J. S., Moran, P. J., Raichle, K., Ferneyhough, K., & Lawton, W. (2002). Patient personality and mortality: A 4- year prospective

examination of chronic renal insufficiency. *Health Psychology, 21,* 315–320. doi: 10.1037/0278-6133.21.4.315

Clusmann, H., Schramm, J., Kral, T., Helmstaedter, C., Ostertun, B., Fimmers, R….. Elger, C. E. (2002). Prognostic factors and outcome after different types of resection for temporal lobe epilepsy. *Journal of Neurosurgery, 97,* 1131– 1141. https://doi.org/10.3171/jns.2002.97.5.1131

Cramer, J., Perrine, K., Devinsky, O., Bryant-Comstock, L., Meador, K., & Hermann, B. (1998). Development and cross-cultural translations of a 31-item quality of life in epilepsy inventory. *Epilepsia, 39,* 81-88. doi: 10.1111/j.1528-1157.1998.tb01278.x

Crawford, J., R., & Henry, J., D. (2004). The positive and negative affect schedule (PANAS): Construct validity, measurement properties and normative data in a large clinical sample. *British Journal of Clinical Psychology, 43,* 245-265. https://doi.org/10.1348/0144665031752934

de Araujo Filho, G. M., Jackowski, A. P., Lin, K., Guaranha, M. S. B., Guilhoto, L. M. F. F., da Silve, H. H…. Yacubian, E. M. (2009). Personality traits related to juvenile myoclonic epilepsy: MRI reveals prefrontal abnormalities through a voxel-based morphometry study. *Epilepsy Behaviour, 14,* 202-207. doi: 10.1016/j.yebeh.2009.03.011

Derogatis, L. R. (1997). The Derogatis Interview for Sexual Functioning (DISF/DISF-SR): An introductory report. *Journal of Sex and Marital Therapy, 23,* 291-304. doi: 10.1080/00926239708403933

Devinsky, O., Vickery, B., Cramer, J., Perrine, K., Hermann, B., & Meador, K. (1995). Development of the quality of life in epilepsy inventory. *Epilepsia, 36,* 1089-1104. https://doi.org/10.1111/j.1528-1157.1995.tb00467.x.

Dilorio, C., Osborne, P., Letz, R., Henry, T., Schomer, D., & Yeager, K. (2003). The association of stigma with self-management and perceptions of health care among adults with epilepsy. *Epilepsy and Behavior, 4,* 259-267. doi: 10.1016/S1525-5050(03)00103-3

Downs, S. H., & Black, N. (1998). The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. *Journal of Epidemiology and Community Health, 52,* 377-384. doi:10.1136/jech.52.6.377

* Endermann, M., & Zimmerman, F. (2009). Factors associated with health-related quality of life, anxiety and depression among young adults with epilepsy and mild cognitive impairments in short-term residential care. *Seizure, 18,* 167-175. doi: 10.1016/j.seizure.2008.08.013

Erlen, K., Stilley, C., Bender, A., Lewis, M., Garand, L., Kim, Y….. Shaler, C. (2011). Personality traits and chronic illness: a comparison of individuals with psychiatric, coronary heart disease, and HIV/AIDS diagnosis. *Applied Nursing Research, 24,* 74-81. doi: 10.1016/j.apnr.2009.04.006

Eysenck, H. J., & Eysenck, S. B. (1964). *Manual of the Eysenck Personality Inventory.* London: University of London Press.

Eysenck, H. J., & Eysenck, S. B. (1989). *EPQ-Cuestionario de personalidad para nirios (EPQ-J) y adulios (EPQ-A) (Manual). 5th ed.* Madrid: TEA Ediciones SA.

Fahrenberg, J., Myrtek, M., Schumacher, J., & Brähler, E. (2000). *Fragebogenzur Lebenszufriedenheit.* Göttingen: Hogrefe Verlag für Psychologie.

Fan, X. D. (1993). General well-being schedule. *Chinese Mental Health Journal, 42,* 8-9. https://doi.org/10.1007/springerreference_184579

Geschwind, N. (1979). Behavioural changes in temporal lobe epilepsy. *Psychological Medicine, 9,* 217-219. https://doi.org/10.1017/S0033291700030713

Goldberg, L. R., Johnson, J. A., Eber, H. W., Hogan, R., Cloninger, M., & Gough, H. (2006). The international personality item pool and the future of public-domain personality measures. *Journal of Research in Personality, 40,* 84–96. doi: 10.1016/j.jrp.2005.08.007

Goldstein, L. H., Holland, L., Soteriou, H., & Mellers, J. D. (2005). Illness representations, coping styles and mood in adults with epilepsy. *Epilepsy Research, 67,* 1-11. doi: 10.1016/j.eplepsyres.2005.06.008

Gong, Y. X. (1986). *Handbook of Eysenck Personality Questionnaire.* Chang Sha: Hunan Medical Univeristy Press.

González, P. S., Fabelo, R., González, D. E., & Iglesias, M. S. (2010). Personality of patients with epilepsy: Multicausal factors. *Revista Mexicana de Neurociencia: Inicio, 11,* 279- 288. Retrieved from http://www.medigraphic.com/cgi-bin/new/resumenI.cgi?IDARTICULO=44650

Goodwine, R., & Engstrom, G. (2002). Personality and the perception of health in the general population. *Psychological Medicine, 32,* 325-332. https://doi.org/10.1017/S0033291701005104

Helgeson, V. S., & Zajdel, M. (2017). Adjusting to chronic health conditions. *Annual Review of Psychology, 68,* 545-571. https://doi.org?10.1371/journal.pone.0129015

Helmstaedter, C., & Gleinbner, U. (1999). *Fragebogen zur Personlichkeit bei zerebralen Erkankungen.* Bonn: Rheinische Friedrich-Wilhems-Universitat.

Helmstaedter, C., Gleissner, U., & Elger, C. (2000). Personality scales in focal epilepsy. *Epilepsia, 41,* 273-276. Retrieved from https://onlinelibrary.wiley.com/journal/15281167

* Helmstaedter, C., & Witt, J., (2012). Multifactorial etiology of interictal behavior in frontal and temporal lobe epilepsy. *Epilepsia, 53,* 1765-1773. doi:10.1111/j.1528-1167.2012.03602.x

* Hendricks, M., Aldenkamp, A., Van der Vlugt, H., Alpherts, W., & Vermeulen, J. (2002). Memory complaints in medically refractory epilepsy: Relationship to epilepsy-related factors. *Epilepsy & Behaviour, 3,* 165–172. doi:10.1006/ebeh.2002.0320

Hermann, C., Buss, U., & Snaith, R. P. (1995). *Hospital anxiety and depression scale: Deutsche version.* Bern: Hans Huber.

Herrmann, D. J., & Neisser, U. (1978). An inventory of memory experiences. In: M. M. Gruneberg, P. E. Morris, & R. N. Sykes (Eds.), *Practical Aspects of Memory (pp. 233-258*). New York, NY: Academic Press.

Hermann, B. P., Seidenberg, M., & Bell, B. (2000). Psychiatric comorbidity in chronic epilepsy: Identification, consequences, and treatment of major depression. *Epilepsia 41,* 31–41. doi: 10.1111/j.1528-1157.2000.tb01522.x

Horsburgh, M. E., Beanlands, H., Locking-Cusolitto, H., Howe, A., & Watson, D. (2000). Personality traits and self care in adults awaiting renal transplantation. *Western Journal of Nursing Research, 22,* 407–437. doi: 10.1177/01939450022044502

***** Huang, C., Hayman-Abello, B., Hayman-Abello, S., Derry, P., & McLachlan, R. (2014). Subjective memory evaluation before and after temporal lobe surgery. *PLoS ONE, 9,* e93382. doi: 10.1317/journal.pone.0093382

Huang, I., Lee J. L., Ketheeswaran, P., Jones, C. M., Revicki, D. A., & Wu, A. W. (2017). Does personality affect health-related quality of life? A systematic review. *PLoS ONE, 12,* e0173806. https://doi.org/10.1371/journal.pone.0173806

Ibrahim, N., Teo, S. S. L., Che Din, N., Abdul-Gafor, A. H., & Ismail, R. (2015). The role of personality and social support in health-related quality in chronic kidney disease patients. *PLoS ONE, 10,* e0129015.https://doi.org/10.1371/journal.pone.0129015

Jones, J. E., Hermann, B. P., Woodard, J. L., Barry, J., Gilliam, F., Kanner, A., & Meador, J. (2005). Screening for major depression in epilepsy with common self-report depression inventories. *Epilepsia, 46,* 731–735. doi: 10.1111/j.1528-1167.2005.49704.x

Kendler, K. S., Gatz, M., Gardner, C. O., & Pederson, N. (2006). Persoanlity and major depression: A Swedish longitudinal, population-based twin study. *Archives of General Psychiatry, 63,* 1113-1120. doi: 10.1001/archpsyc.63.10.1113

Kendler, K. S., Kuhn, J., & Prescott, C. A. (2004). The inter relationship of neuroticism, sex and stressful life events in the prediction of episodes of major depression.

American Journal of Psychiatry, 161, 631-636. https://doi.org/10.1176/appi.ajp.161.4.631

Khan, A., Jacobson, K. C., Gardner, C. O., Prescott, C. A., & Kendler, K., S. (2005). Personality and co-morbidity of common psychiatric disorders. *British Journal of Psychiatry, 186,* 190-196. https://doi.org/10.1192/bjp.186.3.190

Kroger, J. (2007). *Identity Development: Adolescence Through Adulthood: 2nd edition.* Thousand Oaks, CA: Sage Publications.

* Lacey, C., Salzberg, M., & D'Souza, W. (2016). What factors contribute to the risk of depression in epilepsy?—Tasmanian Epilepsy Register Mood Study (TERMS). *Epilepsia, 57,* 516–522. doi:10.1111/epi.13302

Lawson, V. L., Bundy, C., Belcher, J., & Harvey, J. N. (2010). Mediation by illness perceptions of the effect of personality and health threat communication on coping with the diagnosis of diabetes. *British Journal of Health Psychology, 15,* 623–42. doi: 10.1348/135910709X478664

Linehan, M. (2014). *DBT Skills Training Manual 2nd Edition*. New York, NY: Guilford Press

Mao, L. Y., Jing, D., Peng, W. F., Zhang, Y. H., Yu, M. A., Wei, F., & Xin, W. (2012). Interictal personality change and its related factors in epilepsy patients. *Chinese Journal of Neurology, 45,* 224-228. doi: 10.3760/cma.j.issn.1006-7876.2012.04.004

* Margolis, S., Nakhutina, L., Schaffer, S., Grant, A., & Gonzalez, J. (2018). Perceived epilepsy stigma mediates relationships between personality and social well-

being in a diverse epilepsy population. *Epilepsy & Behaviour, 78,* 7-13. https://doi.org/10.1016/j.yebeh.2017.10.023

McCrae, R. R., Costa, P.T., Ostendorf, F., Angleitner, A., Ostenforf, F., Hrebickova, M….. Smith, P. (2000). Nature over Nurture: temperament, personality, and life span development. *Journal of Personality and Social Psychology, 78,* 173-86. https://doi.org/10.1037/022-3514-78.1.173.

Miller, I. W., Keitner, G. I., Whisman, M. A., Ryan, C. E., Epstein, N. B., & Bishop, D. S. (1992). Depressed patients with dysfunctional families: description and course of illness. *Journal of Abnormal Psychology, 101,* 637-646. https://doi.org/10.1037/0021-843x.101.4.637

Moher, D., Shamseer, L., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M…. Stewart, L. (2015). Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews, 4,* 1-9. https://doi.org/10.1186/2046-4053-4-1

* Molleken, D., Richte-Appelt, H., Stodieck, S., & Bengner, T. (2010). Influence of personality on sexual quality of life in epilepsy. *Epileptic Disorders, 12,* 125-32. doi:10.1684/epd.2010.0315

Neeleman, J., Bijil, R., & Ormel, J. (2007). Neuroticism, a central link between somatic and psychiatric morbidity: path analysis of prospective data. *Psychological Medicine, 34,* 521-531. doi: 10.1017/S0033291703001193

Neitzert, C. S., Davis, C., & Kennedy, H. S. (1997). Personality factors related to the prevalence of somatic symptoms and medical complaints in a healthy student population. *British Journal of Medical Psychology, 70,* 93-101. https://doi.org/10.1111/j.2044-8341.1997.tb01889.x

O'Connor, S. R., Tully, M. A., Ryan, B., Bradley, J. M., Baxter, G. D., & McDonough, S. M. (2015). Failure of a numerical quality assessment scale to identify potential risk of bias in a systematic review: a comparison study. *BioMed Central Research Notes, 8,* 224-227. doi: 10.1186/s13104-015-1181-1

Okazaki, M., Ito, M., Adachi, N., Sunaga, A., Simmitsu, N., & Muramatsu, R. (2018). Evaluation of Personality Traits of Patients with Epilepsy Using Revised NEO Personality Inventory (NEO-PI-R). *Journal of the Japan Epilepsy Society, 35,* 675-683. https://doi.org/10.3805/jjes.35.675

***** Olley, B. O. (2001). Perceived stigma: Prevalence and related factors among clinically diagnosed Nigerian individuals with epilepsy. *IFE PsychologIA, 9,* 65-73. http://dx.doi.org/10.4314/ifep.v9i1.23597

Poppe, C., Crombez, G., Hanoulle, I., Vogelaers, D., & Petrovic, M. (2012). Mental quality of life in chronic fatigue is associated with an accommodative coping style and neuroticism: a path analysis. *Quality of Life Research, 21,* 1337–1345. doi: 10.1007/s11136-011-0048-8

RAND. (1990). *Epilepsy surgery inventory-55.* Santa Monica, CA: RAND Health Sciences Program.

Rassart, J., Luyckx, K., Klimstra, T. A., Moons, P., Groven, C., & Weets, I. (2014). Personality and illness adaptation in adults with type 1 diabetes: The intervening role of illness coping and perceptions. *Journal of Clinical Psychology in Medical Settings, 21,* 41–55. doi: 10.1007/s10880-014-9387-2

Ratsep, T., Kallasmaa, T., Pulver, A., & Gross-Paju, K. (2000). Personality as predictor of coping efforts in patients with multiple sclerosis. *Multiple Sclerosis Journal, 6,* 397-402. https://doi.org/10.117/135245850000600607

Reuber, M., Pukrop, R., Bauer, J., Helmstaedter, C., Tessendorf, N., & Elger, C. E. (2003). Outcome in psychogenic non-epileptic seizures: 1 to 10 year follow-up in 164 patients. *Annals of Neurology, 53,* 305-11. https://doi.org/10.1002/ana.3000

Samoocha, D., Bruinvels, D. J., Elbers, N. A., Anema, J. R., & van der Beek, A. J. (2010). Effectiveness of web-based interventions on patient empowerment: A systematic review and meta-analysis. *Journal of Medical Internet Research, 12,* 23. doi: 10.2196/jmir.1286.

Sato, T. (2005). The Eysenck Personality Questionnaire Brief Version: Factor structure and reliability. *Journal of Psychology, 139,* 545-552. doi: 10.3200/JRLP.139.6.545-552

Schwartz, J., & Cummings, J. L. (1988). Psychopathology in epilepsy: an outpatient consultation-liaison experience. *Psychosomatics, 29,* 295– 300. https://doi.org/10.1016/S0033-3182(88)72366-X

Segal, Z., Teasdale, J., & Williams, M. (2002). *Mindfulness-based cognitive therapy for depression.* New York, NY: Guilford Press.

Sirois, F. (2015). Who looks forward to better health? Personality factors and future self-rated health in the context of chronic illness. *International Journal of Behavioral Medicine, 22,* 569–579. DOI 10.1007/s12529-015-9460-8

Spielberger, C. D. (1983). *State-trait anxiety inventory for adults.* PaloAlto, CA: Consulting Psychologists Press.

* Standage, K., & Fenton, G. (1975). Psychiatric symptom profiles of patients with epilepsy: a controlled investigation. *Psychological Medicine, 5,* 152-160. https://doi.org/10.1017/S0033291700056403

Swartz, B. E., Simpkins, F., Halgren, E., Madelkern, M., Brown, C., Kirsdakumtorn, T., & Gee, M. (1996). Visual working memeory in primary generalized epilepsy: an 18FDG-PET study. *Neurology, 47,* 1203-1212. doi: 10.1212/WNL.47.5.1203

Swickert, R., Rodentreter, C., Hittner, J., & Mushrush, J. (2002). Extraversion, social support processes, and stress. *Personality and Individual Differences, 32,* 887-891. https://doi.org/10.1016/S0191-8869(01)00093-9

* Swinkels, W., Emde Boas, W., Kuyk, J., van Dyck, R., & Spinhoven, P. (2006). Interictal depression, anxiety, personality traits, and psychological dissociation in patients with temporal lobe epilepsy (TLE) and extra-TLE. *Epilepsia, 47,* 2092-2103. doi: 10.1111/j.1528-1167.2006.00808.x

Swinkels, W., Duijsens, I., & Spinhoven, P. (2003). Personality disorder traits in patients with epilepsy. *Seizure, 12,* 587–594. https://doi.org/10.1016/S1059-1311(03)00098-0

Tedman, S., Thornton, E., & Baker, G. (1995). Development of a scale to measure core beliefs and perceived self-efficacy in adults with epilepsy. *Seizure, 4,* 221-231, https://doi.org/10.1016/S1059-1311(05)80065-2

Thomas, R. H., Walsh, J., Church, C., Marson, A. G., Baker, A. G., & Rees, M. I. (2014). A comprehensive neuropsychological description of cognition in drug refractory juvenile myclonic epilepsy. *Epilepsy Behaviour, 36,* 124-129. https://doi.org/10.1016/j.yebeh.2014.04.027

***** Uijl, S., Uiterwaal, C., Aldenkamp, A., Carpay, J., Doelman, J., Keizer, K….. van Donselaar, C. (2006). A cross-sectional study of subjective complaints in patients with epilepsy who seem to be well-controlled with anti-epileptic drugs. *Seziure, 15,* 242-248. doi:10.1016/j.seizure.2006.02.009

* Vermeulen, J., Aldenkamp, A., & Alpherts, W. (1993). Memory complaints in epilepsy: correlations with cognitive performance and neuroticism. *Epilepsy Research, 15,* 157-170. doi: 10.1016/0920-1211(93)90096-P

***** Walsh, J., Thomas, R., Church, C., Rees, M., Marson, A., & Baker, G. (2014). Executive functions and psychiatric symptoms in drug-refractory juvenile myoclonic epilepsy. *Epilepsy & Behaviour, 35,* 72-77. http://dx.doi.org/10.1016/j.yebeh.2014.03.026

Watson, D. (1988). Intraindividual and interindividual analyses of positive and negative affect: their relation to health complaints, perceived stress and daily activities. *Journal of Personality and Social Psychology, 54,* 1020-1030. https://doi.org/10.1037//0022-3514.54.6.1020

Watson, D., & Clark, L. A. (1992). On traits and temperament: general and specific factors of emotional experience and their relation to the five-factor model. *Journal of Personality, 60,* 441-476. doi: 10.1111/j.1467-6494.1992.tb00980.x

Watson, D., Clark, L. A., & Tellegan, A. (1988). Development and validation of brief measures of positive and negative affect: The PANAS scales. J*ournal of Personality and Social Psychology, 54,* 1063–107. https://doi.org/10.1037//0022-3514.54.6.1063

Wilde, G. J. S. (1970). *Amsterdamse Biografische Vragenlijst (ABV): Neurotische labiliteit gemeten volgens de vragenlijst methode. 2nd rev. ed. verbeterde uitgave.* Amsterdam: Van Rossen.

Wilson, S. J., Bladin, P. F., & Saling, M. M. (2004). Paradoxical results in the cure of chronic illness: the "burden of normality" as exemplified following seizure surgery. *Epilepsy Behavior, 5*, 13-21. https://doi.org/10.1016/j.yebeh.2003.11.013

* Wilson, S., Wrench, J., McIntosh, A., Bladin, P., & Berkovic, S. (2009). Personality development in the context of intractable epilepsy. *Archives of Neurology, 66,* 68-72. doi:10.1001/archneurol.2008.532

***** Wilson, S., Wrench, J., McIntosh, A., Bladin, P., & Berkovic, S. (2010). Profiles of psychosocial outcome after epilepsy surgery: The role of personality. *Epilepsia, 51,* 1133-1138. doi:10.1111/j.1528-1167.2009.02392.x

Wing, J. K., Birley, J. L. T., Cooper, J. E., Graham, P., & Isaacs, A. D. (1967). Reliability of a procedure for measuring and classifying "present psychiatric state". *British Journal of Psychiatry, 113,* 499-515. https://doi.org/10.1192/bjp.113.498.499

* Witt, J., Hollman, K., & Helmstaedter, C. (2008). The impact of lesions and epilepsy on personality and mood in patients with symptomatic epilepsy: a pre- to postoperative follow-up study. *Epilepsy Research, 82,* 139-146. doi:10.1016/j.eplepsyres.2008.07.011

Xiao, S. Y. (1993). Social support rating scale. *Chinese Mental Health Journal, 42,* 6-7. Retrieved from http://en.oversea.cnki.net/kns55/oldnavi/n_item.aspx?NaviID=55&Flg=local&B

aseID=ZXWS&NaviLink=Fundamental+Medicine%2Fkns55%2Foldnavi%2Fn_list.aspx%3FNaviID%3D55%26Flg%3Dlocal%26Field%3Dhx_sort%26Value%3D00050004%253F%26OrderBy%3Didno%7CChinese+Mental+Health+Journal

Zelinski, E. M., & Gilewski, M. J. (2004). A 10-item Rasch modeled memory self-efficacy scale. *Aging Mental Health*, 8, 293–306. https://doi.org/10.1080/13607860410001709665

Zhang, B. Y. (1993). Type A behavior questionnaire. In B. Xu, & X. D. Wang (Eds.), *Mental-body medicine* (pp. 86-88). Beijing: Chinese Medical Science and Technology Press.

Zhang, X., Li, S., & Deng, Y. (2004). Influence of coping styles and personality characteristics on quality of life in adults with epilepsy. *Chinese Journal of Clinical Rehabilitation, 8*, 2444-2445. Retrieved from https://copac.jisc.ac.uk/id/6474822?style=html&title=Zhongguo%20lin%20chuang%20kang%20fu%20%3DChinese%20journal%20of%20clinical

Zhang, Y. L., & Yang, D. S. (1993). Life Event Scale. *Chinese Mental Health Journal, 36*, 41-43. Retrieved from http://en.oversea.cnki.net/kns55/oldnavi/n_item.aspx?NaviID=55&Flg=local&BaseID=ZXWS&NaviLink=Fundamental+Medicine%2Fkns55%2Foldnavi%2Fn_list.aspx%3FNaviID%3D55%26Flg%3Dlocal%26Field%3Dhx_sort%26Value%3D00050004%253F%26OrderBy%3Didno%7CChinese+Mental+Health+Journal

*Zhu, D., Jin, L., Xie, G., & Xiao, B. (1998). Quality of life and personality in adults with epilepsy. *Epilepsia, 39,* 1208-1212. doi: 10.1111/j.1528-1157.1998.tb01313.x

* Zimmerman, F., & Enderman, M. (2008). Self-proxy agreement and correlates of health-related quality of life in young adults with epilepsy and mild intellectual disabilities. *Epilepsy & Behavior, 13,* 202-211. doi: 10.1016/j.yebeh.2008.02.005

Appendix A

Downs and Black (1998) Checklist

Appendix

Checklist for measuring study quality

Reporting

1. *Is the hypothesis/aim/objective of the study clearly described?*

yes	1
no	0

2. *Are the main outcomes to be measured clearly described in the Introduction or Methods section?*
If the main outcomes are first mentioned in the Results section, the question should be answered no.

yes	1
no	0

3. *Are the characteristics of the patients included in the study clearly described ?*
In cohort studies and trials, inclusion and/or exclusion criteria should be given. In case-control studies, a case-definition and the source for controls should be given.

yes	1
no	0

4. *Are the interventions of interest clearly described?*
Treatments and placebo (where relevant) that are to be compared should be clearly described.

yes	1
no	0

5. *Are the distributions of principal confounders in each group of subjects to be compared clearly described?*
A list of principal confounders is provided.

yes	2
partially	1
no	0

6. *Are the main findings of the study clearly described?*
Simple outcome data (including denominators and numerators) should be reported for all major findings so that the reader can check the major analyses and conclusions. (This question does not cover statistical tests which are considered below).

yes	1
no	0

7. *Does the study provide estimates of the random variability in the data for the main outcomes?*
In non normally distributed data the inter-quartile range of results should be reported. In normally distributed data the standard error, standard deviation or confidence intervals should be reported. If the distribution of the data is not described, it must be assumed that the estimates used were appropriate and the question should be answered yes.

yes	1
no	0

8. *Have all important adverse events that may be a consequence of the intervention been reported?*
This should be answered yes if the study demonstrates that there was a comprehensive attempt to measure adverse events. (A list of possible adverse events is provided).

yes	1
no	0

9. *Have the characteristics of patients lost to follow-up been described?*
This should be answered yes where there were no losses to follow-up or where losses to follow-up were so small that findings would be unaffected by their inclusion. This should be answered no where a study does not report the number of patients lost to follow-up.

yes	1
no	0

10. *Have actual probability values been reported(e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?*

yes	1
no	0

External validity

All the following criteria attempt to address the representativeness of the findings of the study and whether they may be generalised to the population from which the study subjects were derived.

11. *Were the subjects asked to participate in the study representative of the entire population from which they were recruited?*
The study must identify the source population for patients and describe how the patients were selected. Patients would be representative if they comprised the entire source population, an unselected sample of consecutive patients, or a random sample. Random sampling is only feasible where a list of all members of the relevant

population exists. Where a study does not report the proportion of the source population from which the patients are derived, the question should be answered as unable to determine.

yes	1
no	0
unable to determine	0

12. *Were those subjects who were prepared to participate representative of the entire population from which they were recruited?*
The proportion of those asked who agreed should be stated. Validation that the sample was representative would include demonstrating that the distribution of the main confounding factors was the same in the study sample and the source population.

yes	1
no	0
unable to determine	0

13. *Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?*
For the question to be answered yes the study should demonstrate that the intervention was representative of that in use in the source population. The question should be answered no if, for example, the intervention was undertaken in a specialist centre unrepresentative of the hospitals most of the source population would attend.

yes	1
no	0
unable to determine	0

Internal validity - bias

14. *Was an attempt made to blind study subjects to the intervention they have received ?*
For studies where the patients would have no way of knowing which intervention they received, this should be answered yes.

yes	1
no	0
unable to determine	0

15. *Was an attempt made to blind those measuring the main outcomes of the intervention?*

yes	1
no	0
unable to determine	0

16. *If any of the results of the study were based on "data dredging", was this made clear?*
Any analyses that had not been planned at the outset of the study should be clearly indicated. If no retrospective unplanned subgroup analyses were reported, then answer yes.

yes	1
no	0
unable to determine	0

17. *In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls ?*
Where follow-up was the same for all study patients the answer should yes. If different lengths of follow-up were adjusted for by, for example, survival analysis the answer should be yes. Studies where differences in follow-up are ignored should be answered no.

yes	1
no	0
unable to determine	0

18. *Were the statistical tests used to assess the main outcomes appropriate?*
The statistical techniques used must be appropriate to the data. For example non-parametric methods should be used for small sample sizes. Where little statistical analysis has been undertaken but where there is no evidence of bias, the question should be answered yes. If the distribution of the data (normal or not) is not described it must be assumed that the estimates used were appropriate and the question should be answered yes.

yes	1
no	0
unable to determine	0

19. *Was compliance with the intervention/s reliable?*
Where there was non compliance with the allocated treatment or where there was contamination of one group, the question should be answered no. For studies where the effect of any misclassification was likely to bias any association to the null, the question should be answered yes.

yes	1
no	0
unable to determine	0

20. *Were the main outcome measures used accurate (valid and reliable)?*

For studies where the outcome measures are clearly described, the question should be answered yes. For studies which refer to other work or that demonstrates the outcome measures are accurate, the question should be answered as yes.

yes	1
no	0
unable to determine	0

Internal validity - confounding (selection bias)

21. *Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?*
For example, patients for all comparison groups should be selected from the same hospital. The question should be answered unable to determine for cohort and case-control studies where there is no information concerning the source of patients included in the study.

yes	1
no	0
unable to determine	0

22. *Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?*
For a study which does not specify the time period over which patients were recruited, the question should be answered as unable to determine.

yes	1
no	0
unable to determine	0

23. *Were study subjects randomised to intervention groups?*
Studies which state that subjects wererandomised should be answered yes except where method of randomisation would not ensure random allocation. For example alternate allocation would score no because it is predictable.

yes	1
no	0
unable to determine	0

24. *Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?*
All non-randomised studies should be answered no. If assignment was concealed from patients but not from staff, it should be answered no.

yes	1
no	0
unable to determine	0

25. *Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?*
This question should be answered no for trials if: the main conclusions of the study were based on analyses of treatment rather than intention to treat; the distribution of known confounders in the different treatment groups was not described; or the distribution of known confounders differed between the treatment groups but was not taken into account in the analyses. In non-randomised studies if the effect of the main confounders was not investigated or confounding was demonstrated but no adjustment was made in the final analyses the question should be answered as no.

yes	1
no	0
unable to determine	0

26. *Were losses of patients to follow-up taken into account?*
If the numbers of patients lost to follow-up are not reported, the question should be answered as unable to determine. If the proportion lost to follow-up was too small to affect the main findings, the question should be answered yes.

yes	1
no	0
unable to determine	0

Power

27. *Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%?*
Sample sizes have been calculated to detect a difference of x% and y%.

	Size of smallest intervention group	
A	$<n_1$	0
B	n_1-n_2	1
C	n_1-n_2	2
D	n_1-n_2	3
E	n_1-n_2	4
F	n_2+	5

Section Two: Research Report

Self-Compassion, Personality Traits and Adjustment in Epilepsy and Non-Epileptic Attack Disorder

Abstract

Objectives. Self-compassion has been shown to be associated with a set of adaptive coping strategies which in turn explain better adjustment in individuals with chronic illnesses such as inflammatory bowel disease and arthritis. Gratitude and perfectionism have also been shown to be associated with adjustment in some chronic illnesses. The aim of this study was to investigate whether self-compassion, gratitude and perfectionism were associated with adjustment in people with epilepsy (PWE) and people with non-epileptic attack disorder (PWNEAD). Adjustment was measured via coping efficacy, quality of life (QoL), anxiety and depression.

Design. A cross-sectional questionnaire design was employed.

Method. PWE (*N* = 74), PWNEAD (*N* = 46), and controls (*N* = 89), recruited from outpatient seizure clinics and online, completed questionnaires about their self-compassion, personality traits, coping efficacy, QoL, anxiety and depression levels.

Results. Overall self-compassion was shown to be associated with adjustment in PWE and PWNEAD. Self-compassion was found to be negatively related to anxiety and depression in PWE, PWNEAD and controls; and positively related to coping efficacy in PWE and PWNEAD. Self-compassion was also found to be positively related to QoL in PWE and controls; however, this relationship was not found in PWNEAD. Gratitude was positively related to coping efficacy in PWE and PWNEAD but not in controls. No relationship was found between perfectionistic concerns and coping efficacy in any of the three groups but perfectionistic strivings were positively related to coping efficacy in PWE only.

Conclusions. Overall self-compassion and gratitude were shown to be associated with better adjustment in PWE and PWNEAD and perfectionistic strivings associated with better adjustment in PWE. Implications of these findings for psychotherapeutic interventions for individuals with seizure disorders and future research are discussed.

Practitioner Points

- Offering psychotherapies that focus on the development of self-compassion and gratitude may decrease distress in PWE and PWNEAD, and improve adjustment to their condition.

- Research into the efficacy of gratitude and self-compassionate interventions with PWE and PWNEAD is recommended.

- PWE and PWNEAD should be screened for high levels of anxiety and depression and sign posted to appropriate interventions.

- Further research to understand the role of perfectionism in chronic illnesses is needed.

Introduction

Epilepsy and NEAD

Epilepsy and Non Epileptic Attack Disorder (NEAD) are chronic conditions characterised by recurrent seizures. Epileptic seizures are manifestations of signs and symptoms caused by abnormal electric discharges in the brain whereas seizures in NEAD are not associated with abnormal electric activity. Instead non-epileptic attacks are, in most cases, thought to be an involuntary dissociative response to aversive internal or external stimuli involving a loss of self-control (Brown & Reuber, 2016a).

Although epilepsy is most commonly treated with anti-epileptic drugs (AEDs), about one third of patients do not respond to medication (Duncan, Sander, Sisodiya, & Walker, 2006) and in many cases seizures are reduced but do not altogether cease. Psychological interventions are sought by some people with epilepsy (PWE) to increase their quality of life (QoL; Pinikahana, & Dono, 2009). However, there is still limited evidence of effectiveness of psychotherapy for epilepsy (Ramaratnam, Baker, & Goldstein, 2008; Michaelis et al., 2017). This is due in part to previous studies being small scale and therapy outcomes focussing on seizure control (rather than functioning or well-being), which may be difficult to alter through psychotherapy. Ramaratnam et al. (2008) suggest that psychotherapies have not been more effective because our understanding of the psychological problems faced by PWE is limited. The National Institution for Health and Care Excellence (NICE) guidelines for epilepsy (2012) advocate for psychological interventions (cognitive behavioural therapy, relaxation and biofeedback) to be offered in addition to AEDs for the purpose of improving QoL.

The treatment typically recommended for people with NEAD (PWNEAD) is psychotherapy, although there is only limited evidence for the effectiveness of psychological interventions for this disorder (La France, Reuber, & Goldstein, 2012).

Understanding of the psychological mechanisms underlying NEAD remains incomplete (Brown & Reuber, 2016b). Brown and Reuber (2016a; 2016b) have recently reviewed the literature and suggested an integrative cognitive model of NEAD, suitable for psychological formulation and psychotherapy intervention. Long-term seizure and social outcomes are poor if no specific treatment is offered (Reuber & Elger, 2003).

Anxiety and depression are twice as common in PWE than the general population, and even more prevalent in people with PWNEAD (Kerr, 2012). Lower self-esteem was also reported in PWE and PWNEAD compared to controls (Dimaro et al., 2015). Depression has been related to poor seizure control (Margrove, Menash, Thapar, & Kerr, 2009) and anxiety in PWNEAD has been associated with avoidant behaviour tendencies (Bakvis, Spinhoven, Zitman, & Roelofs, 2011; Dimaro et al., 2014). This avoidance can lead to social isolation and loss of self-confidence, which could in turn increase psychological distress and decrease QoL in PWNEAD (Kerr et al., 2011). Several studies suggest that an individual's coping resources are an important determinant of their resilience to epileptic seizures. Kemp, Morley and Anderson (1999) linked adjustment difficulties in PWE to avoidance, doubt regarding the diagnosis and belief in poor containment. Conversely, high resourcefulness has been linked to lower levels of depression and anxiety in PWE (Rosenbaum & Palmon, 1984).

Self-compassion, Coping and Adjustment in Chronic Illness

Self-perceptions (i.e. how people evaluate themselves) have been shown to be an important factor in how individuals adjust to chronic illness *(*de Ridder, Geenen, Kuijer, & Middendorp, 2008). Research suggests that one type of self-perception; self-compassion, may be particularly important for adjustment to chronic illness (Sirois, Molnar, & Hirsch, 2015). Self-compassion is defined by Neff (2003) as taking a kind, accepting and non-judgmental stance towards oneself in times of failure and difficulty.

It comprises three key features that may account for why self-compassionate people are able to cope with stressful life circumstances: (1) self-kindness, (2) common humanity and (3) mindfulness. Research has shown self-compassion to be linked to indicators of adjustment including resilience (Neff, Kirkpaterick, & Rude, 2007), adaptive coping (Allen & Leary, 2010) and lower stress (Sirois, 2014). Understanding the potential of self-compassion for adaptive coping and therefore reducing stress in individuals with chronic illness, and especially epilepsy and NEAD, is important as stress and anxiety may be a trigger or contributor for both epileptic and non-epileptic seizures (Novakova, Harris, Ponnusamy, & Reuber, 2013; Brown & Reuber, 2016a).

There is growing evidence linking self-compassion to more adaptive coping and lower stress in chronic illness populations. For example Pinto-Gouveia, Duarte, Matos and Fraguas (2014) found lower levels of self-compassion related to higher levels of depression and stress in those with cancer and mixed chronic illness, compared to healthy controls. Przezdziecki et al. (2013) also found higher self-compassion linked to lower distress relating to body image in breast cancer patients, and self-compassion has been linked with lower stress, anxiety and shame in HIV patients (Brion, Leary, & Drabkin, 2014). Sirois and Rowse (2016) conclude that the protective role of self-compassion for stress is explained primarily by the set of coping strategies that self-compassionate people use to deal with challenging circumstances. Literature suggests that adaptive and problem focussed coping strategies are beneficial for adjusting to chronic illness (Ax, Gregg, & Jones, 2001). This is because it allows individuals to adapt to the unpredictability, functional limitations and changing demands that chronic illnesses can present.

Individuals with chronic illness, including epilepsy and NEAD, encounter challenges and stressors related to their condition on a regular basis, which can require

using different coping strategies depending on the demand (Gignac, Cott, & Badley, 2000). Successful management of stress therefore relies on the effectiveness of a set of coping strategies. Coping efficacy, appraisals of how successfully one is coping with an illness-related stressor (Gignac et al., 2000), is one way to capture the degree to which a set of coping strategies are effective for managing stress in the context of chronic illness. For example, in studies of people with arthritis, higher coping efficacy was associated with lower psychological distress and better adaptation (Gignac et al., 2000), fewer depressive symptoms (Sale, Gignac, & Hawker, 2008), and greater self-perceived independence (Wang, Badley, & Gignac, 2004). In individuals with irritable bowel disease (IBD), greater use of denial and behavioural disengagement coping was associated with lower coping efficacy (Voth & Sirois, 2009). Sirois et al. (2015) tested the proposition that self-compassionate people with chronic illness would use a diverse set of coping strategies that would promote feeling that they are coping successfully with their illness, and in turn perceive less stress. They found higher self-compassion was associated with a set of adaptive coping strategies which in turn explained greater coping efficacy and lower perceived stress in patients with IBD and arthritis. The current study therefore measures coping efficacy as a primary indicator of adaptive coping and adjustment. It also measures anxiety and depression levels and QoL to assess overall adjustment. In doing so the study investigates the association between self-compassion and adjustment variables (coping efficacy, anxiety and depression and QoL) in PWE and PWNEAD.

Personality Traits, Coping and Adjustment in Chronic Illness

Gratitude. Positive clinical psychology has highlighted a number of personality traits as being potentially beneficial for adjustment to chronic illness (Wood & Tarrier, 2010).

A 2010 review identified gratitude as a key clinically relevant trait that is beneficial for well-being, however concluded that it had been understudied in chronic illness populations (Wood, Froh, & Geraghty, 2010). As a trait, gratitude involves a life orientation toward noticing the positive in life, including both thankfulness to others and a wider sense of appreciation for what one has (Wood, Maltby, Stewart, & Joseph, 2008). Since Wood et al's (2010) review, research has indicated that gratitude is associated with less depressed mood in individuals with breast cancer and heart failure (Mills et al., 2015; Ruini, & Vescovelli, 2013), and enhanced QoL in a mixed chronic illness sample (Eaton, Bradley, & Morrissey, 2014). Furthermore Sirois and Wood (2017) have shown gratitude to be a resilience factor that promotes healthy adjustment in long term chronic illnesses such as IBD and arthritis. Accordingly, the current study aims to test whether gratitude is also associated with a coping efficacy, a marker of adjustment, in epilepsy and NEAD.

Perfectionism. Perfectionism in chronic illness is a particularly underdeveloped area of research. However, there are some indications that perfectionism is a crucial dispositional factor to consider for understanding adjustment to a number of chronic illnesses (Molnar, Sirois, & Methot-Jones, 2016). Trait perfectionism is usually conceptualised as a multidimensional characteristic, with a growing consensus that the existing measures of trait perfectionism consist of two underlying higher-order factors (Sirois & Molnar, 2016). These factors are commonly referred to as Perfectionistic Strivings (PS) and Perfectionistic Concerns (PC) (Dunkley & Balnkstein, 2000; Stoeber & Otto, 2006). PS is a higher order factor that consists of the setting and compulsive striving towards excessively high standards, whereas PC consists of critical self-evaluations and concerns regarding others' evaluations.

Research has established that each of these factors is differentially related to consequential outcomes. Overall PS, which associated with desirable (e.g. achievement motivation) and undesirable (e.g. depression) outcomes (Cox, Enns, & Clara, 2002; Rice & Dellwo, 2002) is considered to be relatively less harmful than PC, which has been shown to be a vulnerability factor for adjustment difficulties in all aspects of living (Mackinnon et al., 2012; Molnar, Reker, Culp, Sadava, & DeCourville, 2006). However in the context of chronic illness Molnar et al. (2016) propose that even in circumstances when perfectionism gives rise to benefits (PS), there is often a price to pay for compulsively pursuing exorbitant standards, especially as chronic illnesses are often out of an individual's control. This creates high levels of stress and in turn, poor adjustment, as stress takes one's focus away from future concerns and compromises adaptive health behaviours (Molnar et al., 2016). Molnar et al. (2016) advocate for future research to test the proposition that both PS and PC will render perfectionists who live with chronic health problems at greater risk for poor adjustment. Therefore, the current study investigated the association between PC, PS and coping efficacy (a marker of adjustment) in PWE and PWNEAD.

The Current Study

Research questions. This study investigates two research questions:

- Is self-compassion associated with coping efficacy, anxiety, depression, and QoL in people in PWE and PWNEAD?
- Are the personality traits gratitude and perfectionism associated with coping efficacy in PWE and PWNEAD?

In order to answer these questions the following aims were identified, and hypotheses generated (Table 1).

Table 1

Aims and hypotheses

Aims	Hypotheses
Primary aim	
• To investigate whether self-compassion is associated with better coping efficacy in PWE and PWNEAD.	1) Self-compassion levels will be lower in both patient groups (epilepsy and NEAD) than in controls. Self-compassion levels with be lower in PWNEAD than PWE. 2) Self-compassion will be positively correlated with coping efficacy in PWE and PWNEAD.
Secondary Aims	
• To explore whether self-compassion is associated with anxiety, depression and QoL in PWE and PWNEAD.	3) Anxiety and depression levels will be higher in PWNEAD, compared to PWE and controls. 4) Levels of self-compassion will be negatively correlated with anxiety and depression in PWE and PWNEAD. 5) Self-compassion will be positively correlated with QoL in PWE and PWNEAD.
• To explore the relationship between personality traits (perfectionism and gratitude), and coping efficacy in people with epilepsy and people with NEAD.	6) Gratitude will be positively correlated with coping efficacy in PWE and PWNEAD. 7) Perfectionistic concerns will be negatively correlated with coping efficacy in PWE and PWNEAD. 8) Perfectionistic strivings will be negatively correlated with coping efficacy in PWE and PWNEAD.

Method

Participants and Recruitment Procedure

The study employed a cross-sectional design. Data were collected from a convenience sample of participants, recruited between July and December 2017.

Epilepsy and NEAD Groups

Clinic recruitment. Participants with diagnoses of epilepsy or NEAD were recruited from a neurology outpatient clinic at a National Health Service (NHS) hospital in the north of England. Invitation letters (Appendix A) and participant information sheets (PIS) (Appendix B) were sent to potential participants with their seizure clinic outpatient appointment letter. This gave participants a minimum of two weeks to contact the researcher with questions and decide whether to take part in the study. The researcher then approached potential participants in clinic before their appointment. Potential recruits had opportunity to ask questions and revisit the PIS with the researcher. Patients were only included if their diagnoses of epilepsy or NEAD were confirmed by the Consultant Neurologist who had seen the patient on the day of their study participation and based on all available clinical data (not invariably including video-EEG confirmation of the diagnosis). Patients with a clinically uncertain diagnosis, or a diagnosis of mixed epilepsy and NEAD were excluded. Participants were only recruited if they were over 16 years of age, able to give informed consent and complete self-report questionnaires independently or with minimal help.

Consent forms (Appendix C) were completed by participants who agreed to participate and three options were given to complete the questionnaire: 1) complete during clinic times that day and hand to the researcher, 2) take the questionnaire home and post back using the stamped addressed envelope provided, 3) give the researcher their email address to receive a link to complete the questionnaire online. Of 128

participants who were approached about the study in clinic 57 returned a completed questionnaire pack.

Social media and online recruitment. Participants were recruited from social media and websites for epilepsy and NEAD self-help. An online advertisement was shared (Appendix D) and a link given to direct interested individuals to an online invitation letter (Appendix E) and PIS (Appendix F). Participants were asked to self-screen using the inclusion criteria, provide informed consent (Appendix G) and General Practitioner (GP) details before completing the questionnaire. Twenty-six participants with NEAD and 37 participants with epilepsy were recruited online. GPs were contacted to confirm diagnosis of online participants (Appendix H). 87.3% of GPs written to replied with diagnosis confirmation within eight weeks. Three self-reported NEAD participants and one self-reported epilepsy participant were confirmed to have a mixed diagnosis of epilepsy and NEAD by their GPs, and were excluded. One participant who reported a 'not sure' diagnosis was confirmed to have a diagnosis of NEAD and one participant who self-reported a diagnosis of epilepsy was confirmed to have no diagnosis of epilepsy or NEAD.

Control Group

Participants were recruited from a notice posted to a university volunteer's mailing list. Inclusion criteria encompassed adults over the age of 16, who did not currently experience seizures and self-reported they had never experienced seizures throughout their lifetime. To take part, participants needed to be able to give informed consent and complete the self-report questionnaires without help. Inclusion and exclusion criteria were explained in an email and participants were asked to self-verify before taking part. A link to an invitation letter (Appendix I) and PIS (Appendix J) were

given. Consent forms (Appendix K) were completed before participants were granted access to the online questionnaires.

Service User Involvement

As part of the design procedure the researcher consulted with service users attending an outpatient seizure clinic at a neighbouring NHS hospital prior to recruitment. Consultation included the relevance and appropriateness of questions, comprehensiveness of instructions and feasibility of questionnaire completion via one of the three options (in clinic, via post or online). As service users expressed interest in completing questionnaires in the three different ways, all three options were kept to maximise possible recruitment. Feedback was received on the PIS and consent form regarding comprehensiveness, inclusivity and relevance. This resulted in changes to the PIS, to emphasise where the data from this study would be stored, and adaptions to the demographic questionnaire to be clearer regarding the inclusivity of seizures participants were asked to record.

Sample Characteristics

Table 2 shows participant characteristics. The overall sample consisted of 209 individuals (74 epilepsy, 46 NEAD, 89 control); 152 who were female and 57 male. Table 3 shows the breakdown of participants recruited in clinic and online.

Table 3
Recruitment of participants.

Group	***Data sets***
Epilepsy	*Clinic: 37* *Online: 37* Overall: 74
NEAD	*Clinic: 20* *Online: 26* Overall: 46
Control	*Online:* 89 Overall: 89
Overall	209

Epilepsy. Of the 74 participants in the epilepsy group (clinic and online recruits) 50 were female and 24 male. The age range was between 17 and 63 (M = 36.0, SD = 11.4) and 47.3% were employed.

NEAD. Of the 46 participants in the NEAD group (clinic and online recruits) 35 were female and 11 male. The age range was between 16 and 65 (M = 39.3, SD = 14.8), 45.7% were receiving disability benefits and 23.9% were employed.

Controls. Of the 89 participants in the epilepsy group 67 were female and 22 male. The age range was between 19 and 79 (M = 36.8, SD = 14.5). The majority of participants were employed (61.8%) and/or at university (47.2%).

Table 2

Participant characteristics

		N	(%)	M	SD
Epilepsy (*N* = 74)					
Gender:	Female	50	(68.6)		
	Male	24	(32.4)		
Age				36.0	11.4
Years in education				13.9	4.9
Employment*:					
	At school/college	1	(1.4)		
	At university	9	(12.2)		
	Employed	35	(47.3)		
	Self-employed	7	(9.5)		
	Unemployed	12	(16.2)		
	Receive disability benefits	20	(27.0)		
	Retired on health-groups	0	(0.0)		
	Receive old age pension	0	(0.0)		
NEAD (*N* = 46)					
Gender:	Female	35	(76.1)		
	Male	11	(23.9)		
Age				39.3	14.8
Years in education				13.2	3.8
Employment*:					
	At school/college	3	(6.5)		
	At university	5	(10.9)		
	Employed	11	(23.9)		
	Self-employed	1	(2.2)		
	Unemployed	10	(21.7)		
	Receive disability benefits	21	(45.7)		
	Retired on health-groups	3	(6.5)		
	Receive old age pension	1	(2.2)		
Control (*N* = 89)					
Gender:	Female	67	(75.3)		
	Male	22	(24.7)		
Age				36.8	14.5
Years in education				16.7	4.4
Employment*:					
	At school/college	0	(0.0)		
	At university	42	(47.2)		
	Employed	55	(61.8)		
	Self-employed	2	(2.3)		
	Unemployed	2	(2.3)		
	Receive disability benefits	0	(0.0)		
	Retired on health-groups	0	(0.0)		
	Receive old age pension	5	(5.6)		

***some participants ticked more than one option and therefore totals >100%**

Measures

Cronbach's alpha (measuring reliability) of each measure used in this study is provided per group in Table 4.

Table 4

Cronbach's alpha data for current study.

	Epilepsy	*NEAD*	*Controls*
SCS-SF	0.80	0.82	0.91
Coping efficacy scale	0.90	0.91	0.88
GQ6	0.79	0.77	0.83
GAD-7	0.92	0.91	0.87
PHQ-9	0.86	0.90	0.90
EQ-5D-3L	0.79	0.68	0.57
SAPS			
-*Discrepancy/PC*	0.89	0.87	0.90
-*Standards/PS*	0.85	0.83	0.88
LSSS-3	0.80	0.73	-

Demographic Questionnaire (Appendix L). Participants provided demographic information including their age, gender, employment, education, overall current health, diagnosis and medication.

Self-Compassion Scale- Short Form (SCS-SF) (Raes, Pommier, Neff, & Van Gucht, 2011) (Appendix M). The SCS-SF is a 12-item inventory designed to measure levels of dispositional self-compassion. Individuals were asked how often they act in self-compassionate ways (e.g. I try to see my failings as part of the human condition) ranging from 1 (*almost never*) to 5 (*almost always*). Six items were reverse scored (e.g.

I'm disapproving and judgemental about my own flaws and inadequacies). The short scale has a near perfect correlation with the long scale (26 items) when examining total scores (r = 0.97). Reliability of the SCS-SF has been demonstrated previously as Raes et al. (2011) report Cronbach's alpha = 0.86. In the current study the SCS-SF was shown to be reliable with Cronbach's alpha $\geq$ .80 for all groups (Table 4).

Coping Efficacy Scale (Gignac et al., 2000) (Appendix N). The coping efficacy scale is a 3-item instrument that measures the extent to which individuals feel they are coping effectively with 1) emotional aspects, 2) day to day problems and 3) the symptoms of their illness. Appropriate adaptations were made for the control group to measure how they feel they were coping with different aspects their life in general e.g. 'I am successfully coping with day to day problems '. A 5-point Likert scale was used to rate responses ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). The scale demonstrated good internal consistency previously (Cronbach's alpha = .79; Gignac et al., 2000) and was shown to be reliable in the current study with Cronbach's alpha > .80 for all groups (Table 4).

Gratitude Questionnaire (McCullough, Emmons, & Tsang, 2002) (Appendix O). The Gratitude Questionnaire-Six-Item Form (GQ-6) is a 6-item self-report questionnaire designed to assess an individual's disposition to experience gratitude in daily life (e.g. I have so much in life to be thankful for). These 6 items are rated on a 7-point Likert scale ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). The GQ-6 correlates substantially with other measures used to assess experiences of gratitude in daily life (McMCulloughat al., 2002). The scale has been shown to be reliable in chronic illness samples (Cronbach's alpha = .92; Mills et al., 2015) and was show to be reliable in the current study with Cronbach's alpha >.70 for all groups (Table 4).

Generalised Anxiety Disorder-7 (GAD-7) (Lowe et al., 2008) (Appendix P). The GAD-7 is a 7-item measure of anxiety. Individuals were asked to rate how much they had been bothered by seven common anxiety symptoms (e.g. trouble relaxing) in the last two weeks on a 4-point scale ranging from 0 (*not at all*) to 3 (*nearly every day*). Level of severity is classified as minimal (0-4), mild (5-9), moderate (10-14), and severe (15-21) with a recommended clinical cut-off at 7. Participants scoring 8 or above can be considered to be suffering from clinically significant anxiety symptoms (Clark et al., 2009). The reliability of the GAD-7 has previously been demonstrated (Cronbach's alpha = 0.89; Lowe at al. 2008) and good reliability was shown in the current study with Cronbach's alpha >.80 for all groups (Table 4).

Patient Health-Questionairre-9 (PHQ-9) (Kroenke, Spitzer, & Williams, 2002) (Appendix Q). The PHQ-9 is a 9-item measure of depression. Individuals were asked to rate how much they had been bothered by nine common depressive symptoms in the last two weeks (e.g. feeling down, depressed or hopeless) on a four-point scale ranging from 0 (*not at all*) to 3 (*nearly every day*). Level of severity is classified as minimal (0-4), mild (5-9), moderate (10-14), moderately-severe (15-19), and severe (20-27) (Kroenke et al., 2001). Respondents scoring 10 or above can be considered to be suffering from clinically significant symptoms of depression (Gilbody, Richards, & Barkham, 2007). The PHQ-9 demonstrated high correlation with another brief depression inventory, high internal reliability (Cronbach's alpha =0.86) and higher PHQ-9 scores were related to overall decreased functional status **(**Kroenke et al., 2002). In the current study the PHQ-9 was show to have good reliability with Cronbach's alpha >.80 for all groups (Table 4).

European Quality of Life – 3 Dimensions Scale (EQ-5D-3L) (Sanchez-Arenas et al., 2014) (Appendix R). The EQ-5D-3L is a standardised, generic measure of QoL. It first presents 5 descriptive items (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression) rated on 3-point scales from 1 (*no problems*) to 3 (*extreme problems*). The digits for the five dimensions can be combined into a 5-digit number describing the patient's health state. After considering these areas of their life a visual analogue scale (VAS) is presented, which records the respondent's global health as a single figure on a vertical 100-point scale. The EQ-5D-3L has been validated by Sanchez-Arenas et al. (2014) who reported the general reliability of 0.80 for patients (older adults) and 0.76 for controls (Cronbach's alphas). However in the current study the EQ-5D-3L did not show high levels (Cronbach's alpha > .70) of reliability in the NEAD or control group (Table 4). Therefore the single VAS score is used in the current study.

Short Almost Perfect Scale (SAPS) (Rice, Richardson & Tueller, 2014) (Appendix S). The SAPS is an 8-item measure of perfectionism created from the previously validated 23-item Almost Perfect Scale- Revised (APS-R) (Slaney, Rice, Mobley, Trippi, & Ashby, 1996). It measures two major dimensions of perfectionism; standards, which corresponds with PS (4 items e.g. I have high expectations of myself) and discrepancy, which corresponds with PC (4 items e.g. doing myself never seems to be enough). Eight items are rated on a 7-point Likert scale ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). Rice et al. (2014) found the SAPS to have good psychometric features including strong item–factor loadings, score reliability (0.85 and 0.87 for standards and discrepancy respectively), and measurement invariance between women and men. In the current study the SAPS was shown to have good reliability with Cronbach's alpha >.80 for both scales in all groups (Table 4).

Liverpool Seizure Severity Scale – Revised (LSSS-3) (Scott-Lennox, Bryant-Comstock, Lennox, & Barker, 2001). (Appendix T). The LSSS-3 is a revised version of the LSSS-2 (Baker, Smith, Jacoby, Hayes, & Chadwick, 1998). It is a 12-item inventory designed to quantify the severity of individual's seizures. It provides a single-unit weighted scale (the itcal scale), ranging from 0-100, that measures the severity of the most severe seizures the individual has experienced during the past 4 weeks. Of the 12 items, nine relate to physical experiences of severe seizures e.g. fall to the ground, urinary incontinence, and are rated from 0 (*I always do this*) to 3 (*I never do this*), and reverse scored. Item 2 relates to losing consciousness and is rated from 0 (*never lose consciousness*) to 4 (*I blank out for more than 5 minutes*). Item 5 related to confusion duration and is rated from 0 (*I never feel confused*) to 5 (*more than 2 hours*). Item 12 relates to duration before 'returning to what I was doing' and is rated from 0 (*less than 1 min*) to 4 (*more than 2 hours*). Reliability of the LSSS-3 has been demonstrated by Cronbach's alpha exceeding 0.7 and validity of the scale is supported by correspondence with physician-rated seizure severity. Scott-Lennox et al. (2001) also found the LSSS-3 was responsive to clinical change. The LSSS-3 has been used widely within the epilepsy population and will also be used for the NEAD group in the current study, as there is currently no available measure of seizure severity for PWNEAD. The LSSS-3 was shown to have good reliability in the current study with Cronbach's alpha >.80 for both epilepsy and NEAD groups (Table 4).

Analysis

Descriptive and statistical analyses were conducted using IBM SPSS statistics software version 23. Summary outcome data for the Epilepsy, NEAD and control groups were individually screened in relation to assumptions for parametric bivariate correlations (normality, linearity, and homoscedasticity) and analysis of variance

(ANOVAs; normality, homogeneity and independence) (Tabachnick & Fidell, 2014). Normality was assessed via investigation of a Q plot, histogram and Shapiro-Wilk test. Homogeneity of variance was assessed using Levene's test and independence of cases assumed from study design. Linearity and homoscedasticity was assessed via investigation of scatter plots and trend lines.

As a result of these screens Mann-Whitney U tests were used to examine differences in seizure variables of epilepsy and NEAD groups. One way ANOVAs and Kruskal-Wallis tests were used to examine differences in self-compassion, anxiety, depression, perfectionism (discrepancy/PC and standards/PS), gratitude and coping efficacy between the three participant groups (epilepsy, NEAD and controls). To reduce the risk of false positive findings associated with multiple tests, a Bonferroni correction was applied to between-group analysis.

Correlations were computed to assess the strength of relationships between self-compassion and; coping efficacy, anxiety, depression, and QoL. Correlations were also used to assess the strength of relations between coping efficacy, gratitude and perfectionism (standards/PS and discrepancy/PC). Analyses were conducted separately for the NEAD and epilepsy groups, and control group data was also analysed for comparison. An alpha of .05 was used to determine significant relationships in correlation analysis.

Power Analysis

A sensitivity power analysis: Hypothesis 1. A sensitivity power analysis was conducted via G*Power3 (Faul, Erdfelder, Buchner, & Lang, 2009) to determine the effect size required to obtain a significant result. The sensitivity power calculation was based on conducting a one way ANOVA for hypothesis 1. From previous seizure research conducted at the host hospital a realistic aim was set to recruit 40 participants

to the epilepsy group and 40 participants to the NEAD group. An aim was also set to recruit 40 participants to the healthy control group resulting in a final sample size of 120 participants in total. In order to achieve 80% power with a sample size of 120 and the significance level of alpha = 0.05, the required effect size was $f = 0.29$ to obtain a significant result. Based on Cohen's (1992) recommendations for between subjects ANOVA's, this falls just above a medium effect size for a one way ANOVA ($f = 0.25$) and was deemed realistic. A recent review of the relevant literature also shows similar effect sizes for similar studies relating to this population (Brown & Reuber, 2016b).

A priori power analysis: Hypothesis 2. A priori power analysis was conducted via G*Power3 (Faul et al., 2009) to determine the sample size required to prevent type II errors (retaining a false null hypothesis) in hypothesis 2. Cohen (1992) recommends a medium effect size of $r = 0.3$ for bivariate correlation. A power analysis for a one-tailed test of significance was conducted as the relationship between the variables in hypothesis 2 was assumed positive. Assuming a significant level of alpha= 0.05 and an effect size of 0.3, a sample size of 67 was required to achieve 80% power.

Ethical Considerations

Ethical approval for this study was obtained from The Wales Research Ethics Committee 6 Proportionate Review Sub-Committee (Appendix U). The participating NHS trust's research and development department also gave approval for this study and acted as a sponsor (Appendix V). Data was anonymised and stored securely to meet ethical requirements. It was clear on all invitation letters, PIS and consent forms that individuals were not obliged to take part in the study and were free to withdraw at any

point without giving a reason. It was stated that withdrawal would have no effect on medical care or services provided to epilepsy and NEAD participants.

Consideration was given to the possibility that the PHQ-9 and GAD-7 may reveal pre-existing high levels of anxiety or depression. If participants scored in the 'severe' range for possible depression or anxiety: 1) the patients' Consultant Neurologist was informed for participants recruited in outpatient clinics and 2) a notification was sent to their GP for participants recruited online (Appendix W). On the PIS participants were encouraged to contact the researcher if they experienced any difficulties with the study measures and contact information for appropriate support services was provided. No financial incentives were offered for taking part in the study.

Results

Data Screening

Missing continuous data from the PNES clinic group (N = 4) and epilepsy clinic group (N = 5) constituted 0.1% of the total data set and was replaced by mean substitution. No outliers were removed to encapsulate all data. Data sets were received from 209 participants; 181 were fully complete and 28 had some missing questionnaires. All participants (N = 209) provided data used for primary analysis pertaining to hypotheses 1 and 2. Table 5 provides a breakdown of data sets and missing questionnaires.

The data from clinic and online recruits for epilepsy and NEAD diagnosis were tested for significant differences between the main dependent variable (SCS-SF). Self-compassion data was shown to be normally distributed in each group and a *t*-test analysis showed no significant differences between online and clinic recruited

participants for both diagnoses. Data were therefore collated to form one overall sample for epilepsy diagnosis and one overall sample for NEAD diagnosis.

Table 5

Data available for analysis

Group	***Data sets***	***Questionnaires missing***
Epilepsy	*Clinic: 37* *Online: 37* Overall: 74	Fully complete data sets: 72 1 data set missing GAD, PHQ and SAPS (clinic recruit) 1 data set missing GAD-7, PHQ-9, VAS and SAPS (clinic recruit)
NEAD	*Clinic: 20* *Online: 26* Overall: 46	Fully complete data sets: 42 2 data sets missing GAD-7, PHQ-9 and SAPS (online recruits) 2 data sets missing SAPS only (clinic recruits)
Control	89	Fully complete data sets: 67 18 data sets missing: GAD-7, PHQ-9 and SAPS 4 data sets missing SAPS only
Overall	209	Fully complete data sets: 181 Data sets with some questionnaires missing: 28

Testing the data for relevant assumptions resulted in violations and recommendation to use non-parametric test equivalents, shown in Table 6. However, parametric tests are more sensitive at detecting differences between samples, or an effect of the independent variable on the dependent variable. Therefore larger samples sizes are often needed to detect any given effects with non-parametric tests. ANOVAs are also considered to be generally robust to violations of normality (Kirk, 2013). To control for this conflict the parametric equivalent of all non-parametric tests carried out were ran to assess for differences in a significant result. Throughout all analysis in this study using a non-parametric test did not make a difference to whether a significant effect or difference was found.

Table 6

Testing of assumptions relating to parametric tests

Hypothesis	Parametric analysis	Dependent variables	Assumption of normality violated? *	Assumption of homogeneity violated?*	Assumption of independent cases violated?*	Assumption of linearity violated?*	Assumption of homoscedasticity violated?*	Analysis applied to test hypothesis
1) Self-compassion levels will be lower in both patient groups (epilepsy and NEAD) than in controls. Self-compassion levels with be lower in PWNEAD than PWE.	One-way unrelated ANOVA with post-hoc test	Self-compassion (SC)	No	No	No	-	-	ANOVA -Bonferroni post hoc test
2) Self-compassion will be positively correlated with coping efficacy in epilepsy and NEAD populations.	Pearson's correlations	SC	No	-	-	-	-	Spearman's correlation
		Coping efficacy	Yes	-	-	-	-	
3) Anxiety and depression levels will be higher in PWNEAD, compared to PWE and controls.	One-way unrelated ANOVAs with post-hoc test	Anxiety	Yes	Yes	No	-	-	Kruskal-Wallis tests - Dunn's pairwise tests
		Depression	Yes	Yes	No			
4) Levels of self-compassion will be negatively correlated with anxiety and depression in PWE and PWNEAD.	Pearson's correlations	SC	No	-	-	-	-	Spearman's correlations
		Anxiety	Yes	-	-	-	-	
		Depression	Yes	-	-	-	-	
5) Self-compassion will be positively correlated with quality of life in PWE and PWNEAD.	Pearson's correlations	SC	No	-	-	No	No	NEAD- Pearson's correlation Epilepsy and control- Spearman's correlation
		Quality of life	Yes (epilepsy and control)	-	-	No	No	
6) Gratitude will be positively correlated coping efficacy in PWE and PWNEAD	Pearson's correlations	Gratitude	No	-	-	No	No	Spearman's correlations
		Coping	Yes	-	-	-	-	

		efficacy						
7) Perfectionistic concerns will be negatively correlated with coping efficacy in PWE and PWNEAD.	Pearson's correlations	Discrepancy/ PC	No	-	-	No	No	Spearman's correlation.
				-	-			
			Yes	-	-	-	-	
		Coping efficacy						
8) Perfectionistic strivings will be negatively correlated with coping efficacy in PWE and PWNEAD.	Pearson's correlations	Standards/PS	Yes	-	-	-	-	Spearman's correlations
		Coping Efficacy	Yes	-	-	-	-	
Additional:	*t*-test	Frequency	Yes	Yes	No	-	-	Mann-Whitney test
Seizure characteristics (between groups analysis).		LSSS score	Yes	Yes	No	-	-	

*results apply to all groups (Epilepsy, NEAD, Control) unless otherwise stated.

Comparison Between-Groups

Statistical comparisons of demographic, seizure and psychological variables between groups are shown in Table 7.

Table 7

Statistical demographic, seizure and psychological comparison between groups

	Epilepsy	*NEAD*	*Controls*	*p*
Demographic Characteristics				
Age: median (IQR*)	35 (17.5)	41 (25.5)	33 (20)	.475
Gender (*n*, %female)	50, 68.6	35, 76.1	67, 75.3	.461
Years in Education: median (IQR)	14 (6)	12.5 (4)	17 (4.5)	< .001**
Seizure Characteristics				
% of individuals experiencing seizures in last 4 weeks	55.4	89.1		
No of seizures per 4 weeks: median (IQR)	5 (10.5)	12 (32)		< .001**
Seizure severity/ictal scale: median (IQR)	61.3 (37.5)	60 (22.5)		.981
Psychological Outcomes				
Self-compassion/ SCS-SF (mean ± SD)	34.5 ± 9.5	31.5 ± 9.3	36.8 ± 9.9	< .001**
Anxiety/ GAD-7: median (IQR)	7 (11)	11 (11)	3 (6)	<.001**
Depression/ PHQ-9: median (IQR)	7.5 (10)	15 (12.8)	3 (6)	<.001**
Perfectionism/ SAPS				
-Discrepancy/PC (mean ± SD)	17.8 ± 6.3	20.1 ± 6.7	22.2 ± 4.6	<.001**
-Standards/PS median (IQR)	22 (7.8)	42.5 (42)	36.5 (13.5)	<.001**
Gratitude/GQ6 : median (IQR)	34 (12.3)	40 (40)	85 (20)	<.001**
Coping efficacy: median (IQR)	10.1 (5.3)	8 (7)	23 (5)	<.001**

**IQR= Interquartile range **significant result (p<.001)*

Demographics. The Kruskal-Wallis test found no significant differences between the mean ranks of age between groups and a significant difference ($p < 0.001$) between the mean ranks of education in at least one pair of groups. Dunn's pairwise tests revealed a significant difference ($p <. 001$, adjusted using Bonferroni correction) between education levels in control and epilepsy groups, and control and NEAD groups. A Pearson's Chi-Squared test found no significant difference in gender between groups.

Seizure characteristics. 55.4% of participants in the epilepsy group reported experiencing a seizure in the last 4 weeks; ranging from 1 to 220 seizures ($M = 6.3$, median = 5, $SD = 26.4$). 89.1% of participants in the NEAD group reported experiencing a seizure in the last 4 weeks; ranging from 1 to 504 seizures ($M = 46.3$, median = 12, $SD = 93.3$). A Mann-Whitney U test showed a significant difference ($U = 2704.5$, $p <. 001$) in seizure frequency in the last four weeks between epilepsy and NEAD groups. NEAD participants had higher seizure frequency than epilepsy participants. No significant difference was found in seizure severity between the two groups.

PC. A one way ANOVA found a significant difference in PC between groups ($F(2,177) = 9.58$, $p <. 001$). A Bonferroni post-hoc test revealed a significant difference between epilepsy and controls. Controls had higher levels of PC ($M = 22.2$, $SD = 4.6$) than epilepsy participants ($M = 17.8$, $SD = 6.3$).

PS. The Kruskal-Wallis test found a significant difference ($p < .001$) between the mean ranks of PS in at least one pair of groups. Dunn's pairwise tests revealed a significant difference ($p < .001$, adjusted using Bonferroni correction) between epilepsy and NEAD groups and epilepsy and controls.

Gratitude. The Kruskal-Wallis test found a significant difference ($p < .001$) between the mean ranks of gratitude in at least one pair of groups. Dunn's pairwise tests revealed a significant difference ($p < .001$, adjusted using Bonferroni correction) between all three groups.

Coping efficacy. The Kruskal-Wallis test found a significant difference ($p < .001$) between the mean ranks of coping efficacy in at least one pair of groups. Dunn's pairwise tests revealed a significant difference ($p <. 001$, adjusted using Bonferroni correction) between control and epilepsy and control and NEAD groups.

Main Results

Findings in relation to aims of the study are presented below. Correlational analysis results are shown in Table 8.

Is self-compassion associated with better coping efficacy? A one way ANOVA found significant difference in self-compassion scores between groups ($F(2,206) = 8.87$, $p <. 001$). A Bonferroni post-hoc test revealed significant differences between the control and two patient samples. Control participants had higher levels of self-compassion ($M = 38.6$, $SD = 9.9$) than epilepsy participants ($M = 34.5$, $SD = 9.5$) and NEAD participants ($M = 31.5$, $SD = 9.3$). No difference was found between epilepsy and NEAD groups.

Self-compassion was positively correlated with coping efficacy in both the epilepsy and NEAD groups (medium/moderate correlations). No relationship was found between self-compassion and coping efficacy in the control group.

Is self-compassion associated with anxiety, depression and QoL? The median score on the GAD-7 was 3 in the control group compared to 7 in the epilepsy group and 11 in the NEAD group. The Kruskal-Wallis test found a significant difference ($p < 0.001$) between the mean ranks of anxiety in at least one pair of groups. Dunn's pairwise tests revealed a significant difference ($p < .001$, adjusted using Bonferroni correction) between anxiety levels in control and epilepsy groups, and control and NEAD groups. No difference was found between the epilepsy and NEAD groups.

The median score on the PHQ-9 was 15 in the NEAD group, 7.5 in the Epilepsy group and 3 in the control group. The Kruskal-Wallis test found a significant difference ($p < 0.001$) between the mean ranks of depression in at least one pair of groups. Dunn's pairwise tests revealed a significant difference in depression levels ($p < .001$, adjusted using Bonferroni correction) between all three groups.

Strong negative correlations were found between self-compassion and anxiety and depression in epilepsy, NEAD and control groups. Self-compassion was positively correlated with QoL in the epilepsy and control groups (moderate correlations). No relationship was found between self-compassion and QoL in the NEAD group.

Are personality traits associated with coping efficacy? Medium positive correlations were found between gratitude and coping efficacy in epilepsy and NEAD groups. No relationship was found between gratitude and coping efficacy in the control group. No relationships were found between PC and coping efficacy in any of the three groups. PS were positively correlated with coping efficacy in the epilepsy group only (moderate correlation).

Table 8

Correlation co-efficient and significance data

	Coping efficacy	Anxiety	Depression	QoL (VAS)	Gratitude	Perfectionism (discrepancy/PC)	Perfectionism (standards/PS)
Epilepsy							
Self-compassion	.40***	-.64***	-.57***	.42***			
Coping efficacy					.48***	-.16	.32**
NEAD							
Self-compassion	.37*	-.74***	-.69***	.18			
Coping efficacy					.38**	-.00	.22
Control							
Self-compassion	.19	-.72***	-.59***	.33**			
Coping efficacy					.13	.04	.08

*$p < .05$ **$p < .01$ ***$p < .001$

Discussion

The aim of this study was to investigate whether self-compassion is associated with adjustment in PWE and PWNEAD. Adjustment was primarily measured via coping efficacy and secondary measures of anxiety, depression and QoL were included. The study explored the relationship between personality traits (perfectionism and gratitude) and coping efficacy, a marker of adjustment, in PWE and PWNEAD. Overall self-compassion was shown to be associated with adjustment in PWE and PWNEAD. Self-compassion was found to be negatively associated with anxiety and depression in

all three groups (PWE, PWNEAD and controls); and positively associated with coping efficacy in PWE and PWNEAD. Self-compassion was also found to be positively associated with QoL in PWE and controls; however, this relationship was not found in PWNEAD. Between-group comparisons found PWE and PWNEAD have lower levels of self-compassion and higher levels of anxiety compared with controls. PWNEAD were found to have the highest levels of depression, followed by PWE and then controls. The result pertaining to personality traits showed gratitude was positively associated with coping efficacy in PWE and PWNEAD but not in controls. No relationship was found between PC and coping efficacy in any of the three groups and PS were positively associated with coping efficacy in PWE only.

Relationship to Clinical Research and Theory

Self-compassion. The finding that self-compassion was positively associated with coping efficacy in PWE and PWNEAD supports the proposition that self-compassion is an important factor in how people with chronic illnesses cope effectively with their condition (Sirios et al., 2015; Sirois & Rouse, 2017). Interestingly, this relationship was not found in controls, and therefore may be specific to people with epilepsy, NEAD and/or other chronic illnesses. This provides support for the suggestion that the protective role of self-compassion is explained primarily by the set of coping strategies self-compassionate people use to deal with challenging circumstances (Sirois & Rouse, 2017). As chronic illnesses present regular unpredictable challenges and stressors, individuals may have to engage in self-compassion to utilise an adaptive set of coping strategies to manage these.

Findings from the current study suggest that these unpredictable stressors and challenges presented by chronic illnesses may serve to make individuals less self-

compassionate overall; as self-compassion was lower in PWE and PWNEAD compared to controls. The tendency to be less self-compassionate in PWE and PWNEAD may be explained by the stress associated with navigating the daily challenges chronic illnesses create e.g. creating uncertainty around attaining personal goals (Hamilton, Karoly, & Kitzman, 2004). This supports previous literature showing that presence of stress in chronic illnesses is associated with low self-compassion (Sirois & Rouse, 2017; Sirois et al., 2015). However the findings from the current study suggest that when PWE and PWNEAD show higher levels of self-compassion, this is associated with coping efficacy and therefore effective adjustment. An association between coping efficacy and adjustment has been found in other chronic illness populations including arthritis (Gignac et al., 2000) and IBD (Voth & Sirois, 2009; Sirois et al., 2015). Furthermore the current study found self-compassion was negatively associated with anxiety and depression and adds to the growing literature that this is a common association in many chronic illnesses (Gignac et al., 2000; Brion et al., 2014; MacBeth & Gumley, 2012). However, in the current study the relationship between self-compassion and anxiety and depression was also observed in controls, and mirrors literature suggesting this is an association present in those without a chronic illness (Leary et al., 2007; Neff, 2003).

Findings are in agreement with previous research suggesting anxiety and depression are more common in PWE and PWNEAD than the general population (Kerr, 2012). They also complement previous findings that depression levels are especially high in PWNEAD, compared to PWE (Kerr, 2012). The study did not, however, replicate findings that this is also the case for anxiety levels (Testa, Lesser, Krauss, & Brandt, 2011; Kerr, 2012). Brown and Reuber (2016b) recently carried out a systematic review which included the investigation of anxiety levels in PWNEAD and PWE. They found that higher levels of anxiety in NEAD populations were apparent in only nine of 28 studies reviewed, and anxiety levels were usually moderately elevated in PWE and

PWNEAD. Therefore high anxiety may be associated with living with a seizure disorder per se rather than NEAD specifically, which would be supported by the current results. Alternatively, increased anxiety levels in NEAD may not have been captured well by the self-report instrument used in this study. Previous research certainly indicates that levels of alexithymia tend to be higher in PWNEAD than those with epilepsy (Brown & Reuber, 2016b), and PWEAD may have difficulties recognising emotional symptoms of anxiety (Goldstein & Mellers, 2006).

Although a positive association was found between self-compassion and QoL in PWE and controls, no association was found in PWNEAD. This is in contrast with previous research suggesting high level of self-compassion is beneficial for QoL in chronic illnesses (Pinto-Gouveia et al., 2014). It may be noteworthy that QoL is measured broadly in the current study using a global measure, and investigating health related QoL or subsets of QoL may have produced different results. Investigating specific areas of QoL in this way has developed the understanding of its relationship to personality factors in epilepsy populations e.g. through its associations with stigma (Margolis, Nakhutina, Schaffer, Grant, & Gonzalez, 2018).

Personality traits. The result showed gratitude was positively associated with adjustment (coping efficacy) in PWE and PWNEAD but not in controls. This is supported by previous research that found gratitude to be associated with healthy adjustment in other chronic illnesses including IBD and arthritis (Sirois & Wood, 2017). Gratitude has also been associated with other markers of adjustment including lower depression levels in individuals with breast cancer and heart failure (Mills et al., 2015; Ruini & Vescovelli, 2013), and enhanced QoL in a mixed chronic illness sample (Eaton et al., 2014). The finding that gratitude and coping efficacy were not associated in

controls was interesting, and suggests this relationship may be specific to chronic illness populations.

No relationship was found between PC and coping efficacy in any of the three groups. This was unexpected as previous literature has shown PC to be associated with adjustment difficulties in all aspects of life (Mackinnon et al., 2012; Molnar et al., 2006) and we therefore hypothesised a negative association been PC and coping efficacy. PS was positively associated with coping efficacy in PWE only. This finding does not support Molnar et al.'s (2016) proposition that PS, as well as PC, is associated with poor adjustment. It instead supports the notion that PS may also be adaptive for coping and adjustment in PWE.

Limitations and Strengths

Limitations of this study include the cross-sectional design limiting conclusions about the direction of causality. Differences in education levels were found between control and patient groups, as were differences in seizure frequency between patient groups that were not controlled for in the analysis. As high levels of alexithymia are found in PWNEAD (Brown & Reuber, 2016b) the study could have also measured levels of alexithymia using a relevant scale (e.g. Toronto Alexithymia Scale; Bagby, Parker, & Taylor, 1994) and controlled for this in analysis. Although a Bonferonni correction was applied for between-group analysis, applying a similar correction for correlational analysis may have further reduced the risk of false positive findings associated with multiple tests. Although efforts were made to confirm participants NEAD and epilepsy diagnoses, it was not a requirement that their diagnosis had been proven by video-EEG. Furthermore diagnoses were not directly verified by the researcher studying medical records. Therefore some participants may have been

misdiagnosed and miscategorised, especially as most PWNEAD are initially misdiagnosed as having epilepsy (Reuber, Fernandez, Bauer, Helmstaedter, & Elger, 2002). It is important to acknowledge that the current study did not measure if participants in the control group had any other types of chronic illnesses, as only controls self-reporting seizure disorders were excluded. This may limit generalisability of findings to those with or without chronic illnesses. Gathering further demographic information, including ethnicity, may have been beneficial to provide a clearer overview of participants.

A strength of this study was the consultation of service users to develop study materials. However, consultation in this way falls within the 'tokenism' category of Arnstein's (1969) ladder of participation, as the consultation gave the service user the right to advise, although the researcher continued to make any final decisions. Involving service user's collaboratively in all areas of the project, from the development of research questions would have been beneficial; however, time and resource constraints prevented this. A further strength of the study was the inclusion of a control group to critically appraise whether findings are specific to PWE and PWNEAD or comparable to the general population. The inclusivity of the recruitment method, encompassing both clinic and online epilepsy and NEAD samples, ensured a wider range of illness experiences were captured than would have been if only one recruitment method used. The sample recruited met the required number of participants calculated by the sensitivity power analysis. However, the NEAD group did not meet the minimum power requirement for a medium effect calculated by the priori power analysis. Nevertheless the number of PWNEAD recruited exceeded group sizes in similar studies recently published within the NEAD literature (Karakis et al., 2014; La France et al., 2011).

Future Directions

As the current study confirms an association between self-compassion and coping efficacy, research measuring or manipulating coping strategies would further develop understanding regarding the function of adaptive or maladaptive coping styles as mediators in this relationship. Future research may also benefit from comparing individuals with well controlled vs. poorly controlled epilepsy, to ascertain whether the predictability of seizures is associated with adjustment to the condition. As causal inferences cannot be drawn from the cross-sectional design, longitudinal designs to study the course of self-compassion and adjustment in PWE and PWNEAD would be beneficial to investigate causality. Investigating health related QoL or breaking down QoL into subsets and investigating the relationship of these with self-compassion in the PWE and PWNEAD may further understanding of this relationship. Further research is needed into the role of gratitude in adjustment to chronic illnesses to ascertain why this association is present in PWE and PWNEAD and not controls, along with studies to test the role of PS and PC in adjustment to chronic illnesses, given the inconsistency with the current findings and previous literature (Molnar et al., 2016).

Clinical Implications

The findings from this study suggest self-compassion is associated with with QoL, anxiety and depression in PWE; and anxiety and depression in PWNEAD. Incorporating self-compassionate exercises into psychotherapy e.g. compassionate based mindfulness (Bartels-Velthuis, Van Der Ploeg, Schroevers, & Van Den Brink, 2015), or offering specific interventions based on self-compassion i.e. compassion focussed therapy (CFT; Gilbert, 2009), compassionate mind training (Gilbert & Procter, 2006) and mindful-self-compassion program (Neff & Gerner, 2013), may be beneficial

to these populations. Gratitude interventions e.g. the use of gratitude diaries, may also be helpful to increase coping efficacy in PWE. Although CFT and other compassionate approaches currently have a plethora of research confirming its effectiveness for anxiety and depression in the general population (Leaviss & Uttley, 2015), future research into self-compassionate and gratitude based interventions to test acceptability and efficacy in the epilepsy and NEAD populations will be important.

Furthermore the findings suggest it would be beneficial for all health-care staff to be aware of the psychological needs of PWE and PWNEAD, especially as they are more likely to suffer with anxiety and depression than the general population. Providing screening for this or asking relevant questions during physical examinations and/or treatment as usual, may highlight early warning signs of these difficulties and identify individuals that require signposting for further support.

Conclusion

This is the first study to investigate the associations between self-compassion, perfectionism, gratitude and adjustment in PWE and PWNEAD. Overall self-compassion and gratitude were shown to be associated with better adjustment in PWE and PWNEAD and PS associated with better adjustment in PWE. Offering psychotherapies focussing on the development of self-compassion and gratitude may decrease distress and increase an individual's ability to cope with and adjust to their condition. Research into the efficacy of these interventions is recommended. Further research is also required to develop understanding into the relationship between self-compassion, personality traits and adjustment, focussing on causality and the mediating factors between these.

References

Allen, A. B., & Leary, M. R. (2010). Self-compassion, stress, and coping. *Social and Personality Psychology Compass, 4,* 107-118. doi: 10.1111/j.1751-9004.2009.00246.x

Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Planning Association, 35,* 216–24. doi: 10.1080/01944366908977225

Ax, S., Gregg, V. H., & Jones, D. (2001). Coping and illness cognitions: Chronic fatigue syndrome. *Clinical Psychological Review, 21,* 161-182. doi: 10.1016/S0272-7358(99)00031-8

Bagby, R. M., Parker, J. D. A. & Taylor, G. J. (1994). The twenty-item Toronto Alexithymia Scale-I. Item selection and cross-validation of the factor structure. Journal of Psychosomatic Research, 38, 23-32. https://doi.org/10.1016/0022-3999(94)90005-1

Baker, G., Smith, D., Jacoby, A., Hayes, J., & Chadwick, D. (1998). Liverpool Seizure Severity Scale revisited. *Seizure-European Journal of Epilepsy, 7,* 201-205. doi: 10.1016/S1059-1311(98)80036-8

Bakvis, P., Spinhoven, P., Zitman, F. G., & Roelofs, K. (2011). Automatic avoidance tendencies in patients with psychogenic non epileptic seizures. *Seizure: European Journal of Epilepsy, 20,* 628-634. doi: 10.1016/j.seizure.2011.06.006

Bartels-Velthuis, A. A., Van Der Ploeg, K., Schroevers, M. J., & Van Den Brink, H. (2015). The Effects of a Mindfulness Based Compassionate Living Training On Anxiety and Depression in a Heterogeneous Sample of Psychiatric Outpatients:

a Pilot Study. *European Psychiatry, 30,* 628-631. doi: 10.1016/S0924-9338(15)30498-3

Brion, J., Leary, M., & Drabkin, A. (2014). Self-compassion and reactions to serious illness: The case of HIV. *Journal of Health Psychology, 19*, 218-229. doi:10.1177/1359105312467391

Brown, R. J., & Reuber, M. (2016a). Towards an integrative theory of psychogenic non-epileptic seizures (PNES). *Clinical Psychology Review, 47*, 55-70. doi: 10.1016/j.cpr.2016.06.003

Brown, R. J., & Reuber, M. (2016b). Psychological and psychiatric aspects of psychogenic non-epileptic seizures (PNES): A systematic review. *Clinical Psychology Review, 45*, 157-82. doi: 10.1016/j.cpr.2016.01.003

Clark, D., Layard, R., Smithies, R., Richards., D., Suckling, R., & Wright, B. (2009). Improving access to psychological therapy: Initial evaluation of two UK demonstration sites. *Behaviour Research and Therapy, 47*, 910-920. doi: 10.1016/j.brat.2009.07.010

Cohen, J. (1992). A power primer. *Psychological Bulletin, 112,* 155-159. doi: 10.1037/0033

Cox, B. J., Enns, M. W., & Clara, I. P. (2002). The multidimensional structure of perfectionism in clinically distressed and college student samples. *Psychological Assessment, 14,* 365–373. doi:10.1037//1040-3590.14.3.365.

De Ridder, D., Geenen, R., Kuijer, R., & Middendorp, H. (2008). Psychological adjustment to chronic disease. *The Lancet, 372,* 19-25. doi:10.1016/S0140-6736(08)61078-8

Dimaro, L., Dawson, D., Roberts, N., Brown, B., Moghaddam, N., & Reuber, M. (2014). Anxiety and avoidance in psychogenic nonepileptic seizures: The role of implicit and explicit anxiety. *Epilepsy & Behavior, 33*, 77–86. doi: 10.1016/j.yebeh.2014.02.016

Dimaro, L., Roberts, N., Moghaddam, N., Dawson, D., Brown, I., & Reuber, M. (2015). Implicit and explicit self-esteem discrepancies in people with psychogenic nonepileptic seizures. *Epilepsy and Behavior*, *46*, 109–117. doi: 10.1016/j.yebeh.2015.03.032

Duncan, J. S., Sander, J. W., Sisodiya, S. M., & Walker, M. C. (2006). Adult epilepsy. *The Lancet, 367,* 1087-1100. doi: 10.1016/S0140-6736(06)68477-8

Dunkley, D. M., & Blankstein, K. R. (2000). Self-critical perfectionism, coping, hassles, and current distress: A structural equation modeling approach. *Cognitive Therapy and Research, 24*, 713–730. doi: 10.1023/A:1005543529245

Eaton, R. J., Bradley, G., & Morrissey, S. (2014). Positive predispositions, quality of life and chronic illness. *Psychology, Health & Medicine*, *19*, 473–489. http://dx.doi.org/10.1080/13548506.2013.824593

Faul, F., Erdfelder, E., Buchner, A., & Lang, A. G. (2009). Statistical power analyses using G*Power 3.1: Tests for correlation and regression analyses. *Behavior Research Methods, 41,* 1149-1160. doi: 10.3758/BRM.41.4.114

Gignac, M. A., Cott, C., & Badley, E. M. (2000). Adaptation to chronic illness and disability and its relationship to perceptions of independence and dependence. *Journal of Gerontology, 55,* 362-372. https://doi.org/10.1093/geronb/55.6.P362

Gilbert, P. (2009). Introducing Compassion Focused Therapy. *BJPsych Advances in Psychiatric Treatment, 15,* 199–208. doi:10.1192/apt.bp.107.005264.

Gilbert, P., & Procter, S. (2006). Compassionate mind training for people with high shame and self-criticism: Overview and pilot study of a group therapy approach. *Clinical Psychology & Psychotherapy, 13,* 353-379. doi: 0.1002/cpp.507

Gilbody, S., Richards, D., & Barkham, M. (2007). Diagnosing depression in primary care using self-completed instruments: UK validation of PHQ–9 and CORE–OM. *British Journal of General Practice, 57,* 650-652. Retrived from http://bjgp.org/content/57/541/650.full

Goldstein, L. H., & Mellers, J. D. (2006). Ictal symptoms of anxiety, avoidance behaviour, and dissociation in patients with dissociative seizures. *Journal of Neurology, Neurosurgery and Psychiatry, 77,* 616-21. doi: 10.1136/jnnp.2005.066878

Hamilton, N. A., Karoly, P., & Kitzman, H. (2004). Self-regulation and chronic pain: The role of emotion. *Cognitive Therapy and Research, 28,* 559-576. doi: 10.1023/B:COTR.0000045565.88145.76

Karakis, I., Montouris, G., Piperidou, C., Luciano, M., Meador, K., & Cole, A. (2014). Patient and caregiver quality of life in psychogenic non-epileptic seizures compared to epileptic seizures. *Seizure, 23,* 47–54. doi:10.1016/j.seizure.2013.09.011

Kerr, M. P. (2012). The impact of epilepsy on patients' lives. *Acta Neurologica Scandinavica, 126,* 1-9. doi: 10.1111/ane.12014

Kerr, M. P., Mensah, S., Besag, F., de Toffol, B., Ettinger, A., Kanemoto, K., … Wilson, S. J. (2011). International consensus clinical practice statements for the treatment of neuropsychiatric conditions associated with epilepsy. *Epilepsia, 52*, 2133-2138. doi: 10.1111/j.1528-1167.2011.03276.x

Kemp, S., Morley, S., & Anderson, E. (1999). Coping with epilepsy: do illness representations play a role? *British Journal of Clinical Psychology, 38*, 43–58. doi: 10.1348/014466599162656

Kirk, R. (2013). *Experimental design: Procedures for the behavioral sciences* (4th ed.). Retrieved from http://dx.doi.org.sheffield.idm.oclc.org/10.4135/9781483384733

Kroenke, K., Spitzer, R., & Williams, J. (2001). The PHQ 9: Validity of a breif depression severity measure. *Journal of General Internal Medicine, 16,* 606–613. doi: 10.1046/j.1525-1497.2001.016009606.x

La France, W., Alosco, M., Davis, J., Tremont, G., Ryan, C., Keitner, G., … Blum, A. (2011). Impact of family functioning on quality of life in patients with psychogenic nonepileptic seizures versus epilepsy. *Epilepsia, 52,* 292–300. doi:10.1111/j.15281167.2010.02765.x

La France, W., Reuber, M., & Goldstein, L. H. (2013). Management of psychogenic non-epileptic seizures. *Epilepsia, 54*, 53-67. doi: 10.1111/epi.12106

Leary, M. R., Tate, E. B., Adams, C. E., Batts-Allen, A., & Hancock, J. (2007). Self-compassion and reactions to unpleasant self-relevant events: The implications of treating oneself kindly. *Journal of Personality and Social Psychology, 92*, 887-904. http://psycnet.apa.org/doiLanding? doi=10.1037%2F0022-3514.92.5.887

Leaviss, J., & Uttley, L. (2015). Psychotherapeutic benefits of compassion-focused therapy: An early systematic review. *Psychological Medicine, 45*, 927-945. doi: 10.1017/S0033291714002141

Lowe, B., Decker, O., Müller, S., Brähler, E., Schellberg, D., Herzog, W., & Herzberg, P. Y. (2008). Validation and standardization of the Generalized Anxiety Disorder Screener (GAD-7) in the general population. *Medical Care, 46*, 266-74. doi: 10.1097/MLR.0b013e318160d093.

MacBeth, A., & Gumley, A. (2012). Exploring compassion: A meta-analysis of the association between self-compassion and psychopathology. *Clinical Psychology Review, 32*, 545-552. doi:http://dx.doi.org/10.1016/j.cpr.2012.06.003

Mackinnon, S., Sherry, S., Antony, M., Stewart, S., Sherry, D., & Hartling, N. (2012). Caught in a bad romance: Perfectionism, conflict, and depression in romantic relationships. *Journal of Family Psychology*, *26*, 215–225. doi:10.1037/a0027402.

Margolis, S., Nakhutina, L., Schaffer, S., Grant, A., & Gonzalez, J. (2018). Perceived epilepsy stigma mediates relationships between personality and social well-being in a diverse epilepsy population. *Epilepsy & Behaviour, 78*, 7-13. https://doi.org/10.1016/j.yebeh.2017.10.023

Margrove, K., Mensah, S., Thapar, A., & Kerr, M. (2011). Depression screening for patients with epilepsy in a primary care setting using the Patient Health Questionnaire-2 and the Neurological Disorders Depression Inventory for Epilepsy. *Epilepsy & Behavior*, 21, 387-390. https://doi.org/10.1016/j.yebeh.2011.05.026

McCullough, M. E., Emmons, R. A., & Tsang, J. A. (2002). The grateful disposition: A conceptual and empirical topography. *Journal of Personality and Social Psychology, 82*, 112–127. doi:10.1037/ 0022-3514.82.1.112.

Michaelis, R., Tang, V., Wagner, J. L., Modi, A. C., LaFrance, W. C., Jr., Goldstein, L. H.… Reuber, M. (2017). Psychological treatments for people with epilepsy. *Cochrane Database of Systematic Reviews, 2017*(10), 1-77. doi: 10.1002/14651858.CD012081.pub2

Mills, P. J., Redwine, L., Wilson, K., Pung, M. A., Chinh, K., Greenberg, B. H., . . .Chopra, D. (2015). The role of gratitude in spiritual well-being in asymptomatic heart failure patients. *Spirituality in Clinical Practice, 2*, 5–17. http://dx.doi.org/10.1037/scp0000050

Molnar, D. S., Reker, D. L., Culp, N. A., Sadava, S. W., & DeCourville, N. H. (2006). A mediated model of perfectionism, affect, and physical health. *Journal of Research in Personality, 40*, 482–500. doi:10.1016/j.jrp.2005.04.002.

Molnar, D., Sirois, F., & Methot-Jones, T. (2016). Trying to be perfect in an imperfect world: Examining the role of perfectionism in the context of chronic illness. In F. Sirois & D. Molnar (Eds.), *Perfectionism, health, and well-being* (pp. 69-99). Cham: Springer.

National Institute for Clinical Excellence (2012). Epilepsies: diagnosis and management (CG137). Retrieved 12.5.18 from: https://www.nice.org.uk/guidance/cg137/chapter/1-Guidance#psychological-interventions

Neff, K. D. (2003). Self-compassion: An alternative conceptualization of a healthy attitude toward oneself. *Self and Identity, 2*, 85-101. doi: 10.1080/15298860390129863

Neff, K. D., & Germer, C. K. (2013). A pilot study and randomized controlled trial of the mindful self-compassion program. *Journal of Clinical Psychology, 69*, 28-44. doi: 10.1002/jclp.21923

Neff, K. D., Kirkpatrick, K. L., & Rude, S. S. (2007). Self-compassion and adaptive psychological functioning. *Journal of Research in Personality, 41*, 139-154. doi: 10.1016/j.jrp.2006.03.004

Novakova, B., Harris, P. R., Ponnusamy, A., & Reuber, M. (2013). The role of stress as a trigger for epileptic seizures: A narrative review of evidence from human and animal studies. *Epilepsia, 54*, 1866-1876. doi: 10.1111/epi.12377

Pinikahana, J., & Dono, J. (2009). The lived experience of initial symptoms of and factors triggering epileptic seizures. *Epilepsy and Behavior, 15*, 513-520. doi: 10.1016/j.yebeh.2009.06.004

Pino-Gouveia, J., Duarte, C., Matos, M., & Fráguas, S. (2014). The protective role of self-compassion in relation to psychopathology symptoms and quality of life in chronic illness and in cancer patients. *Clinical Psychology & Psychotherapy, 21*, 311-323. doi: 10.1002/cpp.1838

Przezdziecki, A., Sherman, K. A., Baillie, A., Taylor, A., Foley, E., & Stalgis-Bilinski, K. (2013). My changed body: breast cancer, body image, distress and self-compassion. *Psychooncology*, 22, 1872-1879. doi: 10.1002/pon.3230

Raes, F., Pommier, E., Neff, K. D., & Van Gucht, D. (2011). Construction and factorial validation of a short form of the Self-Compassion Scale. *Clinical Psychology & Psychotherapy, 18,* 250-255. doi: 10.1002/cpp.702

Ramaratnam, S., Baker, G., & Goldstein, L. (2008). Psychological treatments for epilepsy. *Cochrane Database of Systematic Reviews, 2008*(3), doi: 10.1002/14651858.CD002029.pub3

Reuber. M., & Elger, C. E. (2003). Psychogenic nonepileptic seizures: review and update. *Epilepsy and Behavior, 4,* 205-216. doi: 10.1016/S1525-5050(03)00104-5

Reuber, M., Fernandez, G., Bauer, J., Helmstaedter, C., & Elger, C. E. (2002). Diagnostic delay in psychogenic nonepileptic seizures. *Neurology, 58,* 493-495. doi: 10.1212/WNL.58.3.493

Rice, K., & Dellwo, J. P. (2002). Perfectionism and self-development: Implications for self-esteem, depression, and college adjustment. *Journal of Counseling and Development, 80,* 188– 196. doi:10.1002/j.1556-6678.2002.tb00182.x.

Rice, K., Richardson, C., & Tueller, S. (2014). The short form of the revised almost perfect scale. *Journal of Persoanlity Assessment, 96,* 368-379. doi: 10.1080/00223891.2013.838172

Rosenbaum, M., & Palmon, N. (1984). Helplessness and resourcefulness in coping with epilepsy. *Journal of Consulting and Clinical Psychology, 52,* 244–253. http://dx.doi.org/10.1037/0022-006X.52.2.244

Ruini, C., & Vescovelli, F. (2013). The role of gratitude in breast cancer: Its relationships with post-traumatic growth, psychological well-being and distress.

Journal of Happiness Studies, 14, 263–274. http://dx.doi .org/10.1007/s10902-012-9330-x

Sale, J. E., Gignac, M., & Hawker, G. (2008). The relationship between disease symptoms, life events, coping and treatment, and depression among older adults with osteoarthritis. *The Journal of Rheumatology, 35*, 335-342. Retrieved from http://www.jrheum.org/content/35/2/335.short

Sanchez-Arenas R., Vargas-Alarcon G., Sanchez-Garcia S., Garcia-Peña C., Gutierrez-Gutierrez L., Grijalva, I., … Juárez-Cedillo, T. (2013). Value of EQ-5D in Mexican city older population with and without dementia (SADEM study). *International Journal of Geriatric Psychiatry*, *29*, 478-488. doi: 10.1002/gps.4030

Scott-Lennox, J., Bryant-Comstock, L., Lennox, R., & Baker, G. (2001). Reliability, validity and responsiveness of a revised scoring system for the Liverpool Seizure Severity Scale. *Epilepsy Research, 44,* 53-63. doi: 10.1016/S0920-1211(01)00186-3

Sirois, F. M. (2014). Procrastination and stress: Exploring the role of self-compassion. *Self and Identity, 13*, 128-145. doi: 10.1080/15298868.2013.763404

Sirois, F. M., & Molnar, D. S. (2014). Perfectionism and maladaptive coping styles in patients with chronic fatigue syndrome, irritable bowel syndrome and fibromyalgia/arthritis and in healthy controls. *Psychotherapy and Psychosomatics, 83,* 384–385. doi:10.1159/000365174

Sirois, F. M., Molnar, D. S., & Hirsch, J. K. (2015). Self-compassion, stress, and coping in the context of chronic illness. *Self and Identity*, 1-14. doi: 10.1080/15298868.2014.996249

Sirois, F. M., & Rowse, G. (2016). The role of self-compassion in chronic illness care. *Journal of Clinical Outcomes, 23,* 521-527. Retrieved from http://www.turner-white.com/pdf/jcom_nov16_compassion.pdf

Sirois, F. M., & Wood, A. M. (2017). Gratitude uniquely predicts lower depression in chronic illness populations: A longitudinal study of inflammatory bowel disease and arthritis. *Health Psychology, 32,* 122-132. http://dx.doi.org/10.1037/hea0000436

Slaney, R. B., Rice, K. G., Mobley, M., Trippi, J., & Ashby, J. S. (2001). The revised almost perfect scale. *Measurement and Evaluation in Counseling and Development, 34,* 130. Retrieved from https://search-proquest-com.sheffield.idm.oclc.org/docview/195604085?accountid=13828

Stoeber, J., & Otto, K. (2006). Positive conceptions of perfectionism: Approaches, evidence, challenges. *Personality and Social Psychology Review, 10,* 295–319. doi:10.1207/s15327957pspr1004_2

Tabachnick, B., & Fidell, L. (2007). *Using multivariate statistics* (5th ed.). Boston, MA: Pearson.

Testa, S. M., Lesser, R. P., Krauss, G. L., & Brandt, J. (2012). Personality Assessment Inventory among patients with psychogenic seizures and those with epilepsy. *Eplipsia, 52,* doi: 10.1111/j.1528-1167.2011.03141.x

Voth, J., & Sirois, F. M. (2009). The role of self-blame and responsibility in adjustment to inflammatory bowel disease. *Rehabilitation Psychology, 54,* 99-108. https://doi.org/10.1037/a0014739

Wang, P. P., Badley, E. M., & Gignac, M. (2004). Activity limitation, coping efficacy and self-perceived physical independence in people with disability. *Disability and Rehabilitation*, *26*, 785-793. https://doi.org/10.1080/09638280410001684578

Wood, A. M., Froh, J. J., & Geraghty, A. W. (2010). Gratitude and well-being: A review and theoretical integration. *Clinical Psychology Review*, *30*, 890-905. https://doi.org/10.1016/j.cpr.2010.03.005

Wood, A. M., Maltby, J., Stewart, N., Linley, P. A., & Joseph, S. (2008). A social-cognitive model of trait and state levels of gratitude. *Emotion*, *8*, 281. https://doi.org/10.1037/1528-3542.8.2.281

Wood, A. M., & Tarrier, N. (2010). Positive clinical psychology: A new vision and strategy for integrated research and practice. *Clinical Psychology Review*, *30*, 819-829. https://doi.org/10.1016/j.cpr.2010.06.003

Appendix A

Invitation letter for clinic recruits

Sheffield Teaching Hospitals NHS
NHS Foundation Trust
Excellence as standard

The University Of Sheffield.

Dear Patient,

Re: Self-perceptions and Seizures

We are currently conducting a research study at the Royal Hallamshire Hospital to assess how different self-perceptions are related to how people with seizure disorders cope with their seizures. We are also interested in how these self-perceptions are associated with other aspects of people's lives, for example their mood and well-being.

You have been identified as someone who could take part in this study because you are currently seeing a neurologist at the Royal Hallamshire Hospital.

A participant information sheet is enclosed with this letter. We are sending this information sheet to you so that you can find out about the study and think about taking part. A member of the research team will approach you when you come to the hospital for your appointment and ask you whether you want to take part. This member of the research team will also be able to answer any questions you may have about this study.

Please read the information sheet before you speak to the researcher to help you to understand what the study will involve and provide you with time to think about what your involvement in the study would mean to you.

Some of the data from this study will be used by a postgraduate student of the University of Sheffield as part of an educational project.

If you have any questions please do not hesitate to contact the research supervisor Professor Markus Reuber on 0114 2268763 or Dr Fuschia Sirois on 0114 222 6552 or the research student, Stephanie Clegg, at sclegg2@sheffield.ac.uk. You can also leave a message with the research support officer: 0114 2226650, and Stephanie will call you back at the earliest opportunity.
Your clinical care will not be affected in any way if you do or do not take part in this study. If you do decide to take part in the study you will be free to withdraw at any time.

Kind Regards,

Professor Markus Reuber
Honorary Consultant Neurologist

Appendix B

Participant information sheets for clinic recruits

Sheffield Teaching Hospitals NHS
NHS Foundation Trust
Excellence as standard

The University Of Sheffield.

PARTICIPANT INFORMATION SHEET

Title of Project: Self-perceptions and seizures

Name of Researchers: Stephanie Clegg, Dr Fuschia Sirois and Prof Markus Reuber

We would like to invite you to take part in a research study. Before you decide whether to take part, you should understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Please contact us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

Background

Epilepsy and non-epileptic attack disorder (NEAD) are chronic, disabling conditions that can cause people to become anxious, worried and low in mood. Research has shown that people living with other long-term, chronic conditions cope differently with their illness depending on the way they view themselves. These different self-perceptions can influence how well people with long-term health problems manage to live with their conditions.

This study is being carried out as part of a Doctor of Clinical Psychology (DClinPsy) research project based at the University of Sheffield.

What is the purpose of the study?

The purpose of this study is to assess how self-compassion, gratitude and perfectionism are related to how people with seizure disorders cope with their seizures. We are also interested in how self-compassion, gratitude and perfectionism are associated with other aspects of people's lives, for example their mood and well-being.

Why have I been asked to take part?
We are approaching people who have experienced seizures and who have been seeing a neurologist at the Royal Hallamshire Hospital in Sheffield. We are asking people with epileptic seizures as well as people with non-epileptic attacks to take part in this study. Right now, we only want to inform you about the study. You do not have to decide whether you want to take part until you go to the hospital for your appointment in the neurology outpatient clinic, where you will have an opportunity to ask a researcher any questions you have about the study.

Do I have to take part?
It is up to you to decide whether or not to take part. If you have any questions about this study at any time, you can contact us or write them down and ask the researcher on the day of your clinic appointment. If you do decide to take part you are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive in any way.

What will happen to me if I take part?
When you attend the appointment in the neurology clinic at the Royal Hallamshire Hospital, you will have a chance to ask questions, before we would ask you to sign a consent form to record your agreement to take part. At the time of your appointment, you would also be asked to complete a set of questionnaires, which should take no longer than 30 minutes.

What are the possible benefits of this study? As self-perceptions in relation to coping has not been extensively studied in people with seizures before, it is hoped the findings from this research will contribute towards better care for this population in the future.

What are the possible risks of taking part in this study?
There are no significant risks associated with taking part in the study. Two of the questionnaires ask about symptoms of depression and anxiety. If completion of these questionnaires raises any issues or concerns, the research team, medical and nursing staff in the clinic will offer support. We can also provide you with details of services and organisations you can contact for further support. The researchers would also inform your clinician if you were likely to have anxiety or depression requiring treatment.

Will my taking part in this study be kept confidential?
All the information that is collected about you during this study will be kept strictly confidential. We will keep your personal details, such as name and email address, separately to your questionnaire responses and locked in a secure location. This means that your identity will be kept private. Any personal details held by us will be destroyed once the study has finished. Anonymous study data will be kept for 10 years and then destroyed. We would only pass on clinically

relevant findings (for instance from anxiety or depression questionnaires) to your consultant neurologist. We may also share information if there is a concern about a potential risk to yourself or another person.

What will happen to the results of the study?
The results of this study will contribute to a Doctor of Clinical Psychology (DClinPsy) thesis. We will also publish the results of the study in a scientific journal. You will not be identified individually in the write-up. If you would like a summary of the results of the study once it is complete, please let us know.

What if I change my mind?
You do not have to take part in this study. If you have agreed to take part, you can stop at any time without giving your reasons. This will have no effect on any services you are receiving.

Research funding
This research project is funded by the University of Sheffield.

Who has reviewed this study?
The Wales Research Ethics Committee 6 Proportionate Review Sub-Committee has reviewed this study and found it to be ethically sound.

Who should I contact if I have a question or need more information?
Stephanie Clegg
Clinical Psychology Unit
The University of Sheffield
Cathedral Court Floor F
1 Vicar Lane
Sheffield
S1 2LT
UK

Email: sclegg2@sheffield.ac.uk

You can also leave a message with the research support officer: 0114 2226650, and Stephanie will call you back at the earliest opportunity.

What if something goes wrong?
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact Sheffield Patient Services Team (previously known as PALS) on 0114 2712400. Alternatively you can write to Sheffield Teaching Hospitals NHS

Foundation Trust regarding your concerns by sending a letter to the Chief Executive. All written complaints should be sent to

Sir Andrew Cash,
Chief Executive,
Sheffield Teaching Hospitals NHS Foundation Trust,
8 Beech Hill Road,
Sheffield,
S10 2SB

Alternatively you can outline your concerns by filling out an anonymous online feedback form provided by Sheffield Teaching Hospitals NHS Foundation Trust at: https://www.sth.nhs.uk/patients/patient-experience/feedback/leave-feedback.

Organisations for further support

NHS Direct
Tel: 0845 46 47
Website: www.nhsdirect.nhs.uk

Mind, the mental health charity
Tel: 0300 123 3393
Website: www.mind.org.uk

Samaritans
Tel: 08457 90 90 90
Website: www.samaritans.org

Breathing Space
Tel: 0800 83 85 87
Website: www.breathingspacescotland.co.uk

Epilepsy Action
Tel: 0808 800 5050
Website: https://www.epilepsy.org.uk

Epilepsy Society
Tel: 01494 601 400
Website: http://www.epilepsysociety.org.uk

Appendix C

Consent form for clinic recruits

Sheffield Teaching Hospitals NHS
NHS Foundation Trust
Excellence as standard

The University Of Sheffield.

CONSENT FORM - Patient Participant

Title of Project: Self-perceptions and seizures

Name of Researchers: Stephanie Clegg, Dr. Fuschia Sirois, Prof Markus Reuber

	Please initial box
1. I confirm that I have read and understand the information sheet version ___ dated ____ for the above study and have had the opportunity to ask questions.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	☐
3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by members of the research team from the University of Sheffield, regulatory authorities or representatives from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records and for my diagnosis to be checked from my records.	☐
4. I agree to provide my email address (if applicable) to a member of the research team and give permission to be contacted with an electronic questionnaire option if I cannot complete the questionnaire during clinic waiting times. I understand I can also post the paper copy back using the freepost envelope if I prefer.	☐
5. I agree to take part in the above study and understand that the data will be used as part of a Doctor of Clinical Psychology (DClinPsy) degree thesis.	☐

Name of participant _____ Date _____ Signature _____

Email address of participant _____

Name of person taking consent _____ Date _____ Signature _____

When complete: 1 copy for patient, 1 original for researcher site file, 1 copy for medical notes.

Appendix D

Online advertisement for participants

Online recruitment materials.

Seizure groups

A link was posted on social media websites and self-help group websites with the following text:

‘’Do you suffer from epilepsy or non-epileptic attack disorder? We are currently conducting a short questionnaire to assess how different self-perceptions (self-compassion, gratitude, perfectionism) are related to how individuals with epilepsy and non-epileptic attack disorder cope with their seizures. We are also interested in how these self-perceptions are associated with other aspects of people’s lives, for example their mood and well-being. Please click on the link to find out more and how to get involved.’’

Participants were then directed to the participant information sheet explaining the study in more detail.

Control group

A link was posted on the university volunteer’s mailing list with the following text:

‘We are currently conducting a short questionnaire to assess how different self-perceptions (self-compassion, gratitude, perfectionism) are related to how individuals cope with difficult life events. We are also interested in how these self-perceptions are associated with other aspects of people’s lives, for example their mood and well-being. Please click on the link to find out more and how to get involved.’

Participants were then directed to the participant information sheet explaining the study in more detail.

Appendix E

Invitation letter for online seizure recruits

Sheffield Teaching Hospitals NHS
NHS Foundation Trust
Excellence as standard

The University Of Sheffield.

Dear Potential Participant,

Re: Self-perceptions and Seizures

We are currently conducting a research study to assess how different self-perceptions are related to how people with seizure disorders cope with their seizures. We are also interested in how these self-perceptions are associated with other aspects of people's lives, for example their mood and well-being.

A participant information sheet can be found by clicking on the link at the end of this letter. This information sheet is so that you can find out about the study and think about taking part. It is up to you whether you would like to take part.

Please read the information sheet before you speak to the researchers (details below) to help you to understand what the study will involve and provide you with time to think about what your involvement in the study would mean to you.

Some of the data from this study will be used by a postgraduate student of the University of Sheffield as part of an educational project.

If you have any questions please do not hesitate to contact the research supervisors Professor Markus Reuber on 0114 2268763 or Dr Fuschia Sirois on 0114 222 6552 or the research student, Stephanie Clegg, at sclegg2@sheffield.ac.uk. You can also leave a message with the research support officer, Amrit Sinha on 0114 2226650, and Stephanie will call you back at the earliest opportunity.

Your clinical care will not be affected in any way if you do or do not take part in this study. If you do decide to take part in the study you will be free to withdraw at any time.

Kind Regards,

Professor Markus Reuber	Dr Fuschia Sirois	Stephanie Clegg
Honorary Consultant Neurologist	Reader in Social and Health Psychology	DClinPsy Student

Appendix F

Participant information sheets for online seizure recruits

Sheffield Teaching Hospitals NHS
NHS Foundation Trust
Excellence as standard

The University Of Sheffield.

PARTICIPANT INFORMATION SHEET

Title of Project: Self-perceptions and seizures

Name of Researchers: Stephanie Clegg, Dr. Fuschia Sirois and Prof Markus Reuber

We would like to invite you to take part in a research study. Before you decide whether to take part, you should understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Please contact us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

Background

Epilepsy and non-epileptic attack disorder (NEAD) are chronic, disabling conditions that can cause people to become anxious, worried and low in mood. Research has shown that people living with other long-term, chronic conditions cope differently with their illness depending on the way they view themselves. These different self-perceptions can influence how well people with long-term health problems manage to live with their conditions.

This study is being carried out as part of a Doctor of Clinical Psychology (DClinPsy) research project based at the University of Sheffield.

What is the purpose of the study?

The purpose of this study is to assess how self-compassion, gratitude and perfectionism are related to how people with seizure disorders cope with their seizures. We are also interested in how self-compassion, gratitude and perfectionism are associated with other aspects of people's lives, for example their mood and well-being.

Why have I been asked to take part?

We are approaching people who have experienced epileptic seizures as well as people with non-epileptic attacks to take part in this study. Right now, we only want to inform you about the study. You do not have to decide whether you

want to take part until you are ready to do so. When you are ready you can click on the link to take you to the questionnaire that you can complete online.

Do I have to take part?
No. It is up to you to decide whether or not to take part. If you have any questions about this study you can contact us using the details at the end of this form. If you do decide to take part you are free to withdraw at any time, without giving a reason. This would not affect the standard of care or service you receive in any way.

What will happen to me if I take part?
When you click the link to take you to the next page we will ask you to sign a consent form to record your agreement to take part. You will then be put through to the online questionnaire and asked to complete a set of questions, which should take no longer than 30 minutes. We will also write to your General Practitioner (GP) to confirm your diagnosis using the GP details you provide.

What are the possible benefits of this study?
As self-perceptions in relation to coping has not been extensively studied in people with seizures before, it is hoped the findings from this research will contribute towards better care for this population in the future.

What are the possible risks of taking part in this study?
There are no significant risks associated with taking part in the study. Two of the questionnaires ask about symptoms of depression and anxiety. If completion of these questionnaires raises any issues or concerns please contact the research staff using the details at the end of this page or your GP. We can also provide you with details of services and organisations you can contact for further support. The researchers would also inform your GP if you were likely to have anxiety or depression requiring treatment.

Will my taking part in this study be kept confidential?
All the information that is collected about you during this study will be kept strictly confidential. We will keep your personal details, such as name and email address, separately to your questionnaire responses and password protect all electronic documents. This means that your identity will be kept private. Any personal details held by us will be destroyed once the study has finished. Anonymous study data will be kept for 10 years and then destroyed. We would only pass on clinically relevant findings (for instance from anxiety or depression questionnaires) to your GP. We may also share information if there is a concern about a potential risk to yourself or another person.

What will happen to the results of the study?
The results of this study will contribute to a Doctor of Clinical Psychology (DClinPsy) thesis. We will also publish the results of the study in a scientific

journal. You will not be identified individually in the write-up. If you would like a summary of the results of the study once it is complete, please let us know.

What if I change my mind?
You do not have to take part in this study. If you have agreed to take part, you can stop at any time without giving your reasons. This will have no effect on any services you are receiving.

Research funding
This research project is funded by the University of Sheffield.

Who has reviewed this study?
The Wales Research Ethics Committee 6 Proportionate Review Sub-Committee has reviewed this study and found it to be ethically sound.

Who should I contact if I have a question or need more information?
Stephanie Clegg
Clinical Psychology Unit
The University of Sheffield
Cathedral Court Floor F
1 Vicar Lane
Sheffield
S1 2LT
UK

Email: sclegg2@sheffield.ac.uk

You can also leave a message with the research support officer: 0114 2226650, and Stephanie will call you back at the earliest opportunity.

What if something goes wrong?
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact Sheffield Patient Services Team (previously known as PALS) on 0114 2712400. Alternatively you can write to Sheffield Teaching Hospitals NHS Foundation Trust regarding your concerns by sending a letter to the Chief Executive. All written complaints should be sent to

Sir Andrew Cash,
Chief Executive,
Sheffield Teaching Hospitals NHS Foundation Trust,
8 Beech Hill Road,
Sheffield,
S10 2SB

Alternatively you can outline your concerns by filling out an anonymous online feedback form provided by Sheffield Teaching Hospitals NHS Foundation Trust at: https://www.sth.nhs.uk/patients/patient-experience/feedback/leave-feedback.

Organisations for further support

NHS Direct
Tel: 0845 46 47
Website: www.nhsdirect.nhs.uk

Mind, the mental health charity
Tel: 0300 123 3393
Website: www.mind.org.uk

Samaritans
Tel: 08457 90 90 90
Website: www.samaritans.org

Breathing Space
Tel: 0800 83 85 87
Website: www.breathingspacescotland.co.uk

Epilepsy Action
Tel: 0808 800 5050
Website: https://www.epilepsy.org.uk

Epilepsy Society
Tel: 01494 601 400
Website: http://www.epilepsysociety.org.uk

Appendix G

Consent forms for online seizure recruits

Sheffield Teaching Hospitals NHS
NHS Foundation Trust
Excellence as standard

The University Of Sheffield.

CONSENT FORM – Online Patient Participant

Title of Project: Self-perceptions and seizures

Name of Researchers: Stephanie Clegg, Dr. Fuschia Sirois, Prof Markus Reuber

	Please initial box
1. I confirm that I have read and understand the information sheet version___ dated ___ for the above study and have had the opportunity to ask questions.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	☐
3. I understand that data collected during the study may be looked at by members of the research team from the University of Sheffield, regulatory authorities or representatives from the NHS Trust. I give permission for these individuals to have access to my data.	☐
4. I agree that the research team can contact my General Practitioner to confirm my medical diagnosis	☐
5. I agree that the research team can inform my General Practitioner about evidence of likely anxiety or depression	☐
6. I agree to take part in the above study and understand that the data will be used as part of a Doctor of Clinical Psychology (DClinPsy) degree thesis.	☐

_____ _____ _____
Name Date Signature

GP details

GP: _____

Practice: _____

Appendix H

GP letter to confirm diagnosis of online seizure recruits

Academic Neurology Unit,
Royal Hallamshire Hospital,
Glossop Road,
Sheffield.

DATE

SELF-PERCEPTIONS AND SEIZURES (STH 19617)

Re: DOB

Dear

This patient has agreed to take part in the above research project conducted by a research team based at the Sheffield Teaching Hospitals NHS Foundation Trust and the University of Sheffield. Details of the study are described in the enclosed Participant Information Sheet.

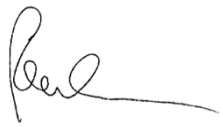
We would be grateful if you could confirm your patient's diagnosis using the enclosed form and freepost return envelope. We enclose a copy of the electronically signed and dated consent form from your patient, allowing you to share this information with us.

Should you require any further details about this study please contact our researcher Stephanie Clegg, Clinical Psychology Unit, 1 Vicar Lane, Sheffield, S1 2LT, sclegg2@sheffield.ac.uk.

We value your involvement in our work with your patient.

With best wishes

Yours sincerely



Professor Markus Reuber,

Honorary Consultant Neurologist (MD, PhD, FRCP).

SELF-PERCEPTIONS AND SEIZURES (STH 19617)

I confirm the patient has a diagnosis of: (please tick)

- ○ Epilepsy
- ○ Nonepileptic attack disorder / dissociative seizures / psychogenic nonepileptic seizures
- ○ Mixed seizures (epilepsy AND nonepileptic seizures)

Any other information that you may feel would be relevant or useful for researchers to know:

……

……

……

……

……

……

……

……

Please print name: ……

Your position: ……

Your signature: ……

Todays date: ……

Please place the completed form in the free post envelope that we have provided.

Thank you for your time

Appendix I

Invitation letter for controls

Sheffield Teaching Hospitals NHS
NHS Foundation Trust
Excellence as standard

The University Of Sheffield.

Dear Potential Participant,

Re: Self-perceptions and Seizures

We are currently conducting a research study to assess how different self-perceptions are related to how people with seizure disorders cope with their seizures. We are also interested in how these self-perceptions are associated with other aspects of people's lives, for example their mood and well-being. We are approaching people who do not experience seizures and have never experienced seizures in the past to form part of a control group. The results from this control group will be measured against the results from people suffering with epilepsy and non-epileptic attack disorder (NEAD) to see if there are any significant differences in self-perceptions, anxiety and depression levels and coping with difficult events.

A participant information sheet is attached to this letter (hard copy) or can be found by clicking on the link at the end of this letter (if reading this electronically). This information sheet is so that you can find out about the study and think about taking part. It is up to you whether you would like to take part.

Please read the information sheet before you speak to the researchers (details below) to help you to understand what the study will involve and provide you with time to think about what your involvement in the study would mean to you.

Some of the data from this study will be used by a postgraduate student of the University of Sheffield as part of an educational project.

If you have any questions please do not hesitate to contact the research supervisors Professor Markus Reuber on 0114 2268763 or Dr Fuschia Sirois on 0114 222 6552 or the research student, Stephanie Clegg, at sclegg2@sheffield.ac.uk. You can also leave a message with the research support officer, Amit Sinha on 0114 2226650, and Stephanie will call you back at the earliest opportunity.

It is up to you whether or not you decide to take part in this study. If you do decide to take part in the study you will be free to withdraw at any time.

Kind Regards,

Professor Markus Reuber	Dr Fuschia Sirois	Stephanie Clegg
Honorary Consultant Neurologist	Reader in Social and Health Psychology	DClinPsy Student

Appendix J

Participant information sheets for controls

Sheffield Teaching Hospitals NHS
NHS Foundation Trust
Excellence as standard

The University Of Sheffield.

PARTICIPANT INFORMATION SHEET

Title of Project: Self-perceptions and coping with seizures

Name of Researchers: Stephanie Clegg, Dr Fuschia Sirois and Prof Markus Reuber

We would like to invite you to take part in a research study. Before you decide whether to take part, you should understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Please contact us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

Background

Epilepsy and non-epileptic attack disorder (NEAD) are chronic, disabling conditions that can cause people to become anxious, worried and low in mood. Research has shown that people living with other long-term, chronic conditions cope differently with their illness depending on the way they view themselves. These different self-perceptions can influence how well people with long-term health problems manage to live with their conditions.

This study is being carried out as part of a Doctor of Clinical Psychology (DClinPsy) research project based at the University of Sheffield.

What is the purpose of the study?

The purpose of this study is to assess how different self-perceptions are related to how people with seizure disorders cope with their seizures. We are also interested in how these self-perceptions are associated with other aspects of people's lives, for example their mood and well-being.

Why have I been asked to take part?

We are approaching people who do not experience seizures and have never experienced seizures in the past to form part of a control group. The results from this control group will be measured against the results from people suffering with epilepsy and NEAD to see if there are any significant differences in self-perceptions, anxiety and depression levels and coping with difficult events.

Do I have to take part?
It is up to you to decide whether or not to take part. If you have any questions about this study at any time, you can contact the researchers via email. If you do decide to take part you are free to withdraw at any time, without giving a reason.

What will happen to me if I take part?
After reading this information sheet you will be asked to complete a consent form. Once this has been completed, if you are participating electronically, a link will appear to an online questionnaire site. You will be asked to complete a set of questionnaires, which should take no longer than 30 minutes. If you are participating using pen and paper, you can go on to complete the hard copy of the questionnaire.

What are the possible benefits of this study?
As self-perceptions in relation to coping have not been extensively studied in people with seizures before, it is hoped the findings from this research will contribute towards better care for this population in the future.

What are the possible risks of taking part in this study?
There are no significant risks associated with taking part in the study. Two of the questionnaires ask about symptoms of depression and anxiety. If completion of these questionnaires raises any issues or concerns please contact one of the researchers involved in the project. We can also provide you with details of services and organisations you can contact for further support. The researchers would also inform your GP if you were likely to have anxiety or depression requiring treatment.

Will my taking part in this study be kept confidential?
All the information that is collected about you during this study will be kept strictly confidential. We will keep your personal details, such as name and email address, separately to your questionnaire responses and locked in a secure location. This means that your identity will be kept private. Any personal details held by us will be destroyed once the study has finished. Anonymous study data will be kept for 10 years and then destroyed. We would only pass on a notification to your GP if you scored high levels of anxiety or depression. We may also share information if there is a concern about a potential risk to yourself or another person.

What will happen to the results of the study?
The results of this study will contribute to a Doctor of Clinical Psychology (DClinPsy) thesis. We will also publish the results of the study in a scientific journal. You will not be identified individually in the write-up. If you would like a summary of the results of the study once it is complete, please let us know.

What if I change my mind?
You do not have to take part in this study. If you have agreed to take part, you can stop at any time without giving your reasons.

Research funding
This research project is funded by the University of Sheffield.

Who has reviewed this study?
The Wales Research Ethics Committee 6 Proportionate Review Sub-Committee has reviewed this study and found it to be ethically sound.

Who should I contact if I have a question or need more information?
Stephanie Clegg
Clinical Psychology Unit
The University of Sheffield
Cathedral Court Floor F
1 Vicar Lane
Sheffield
S1 2LT
UK

Email: sclegg2@sheffield.ac.uk

You can also leave a message with the research support officer: 0114 2226650, and Stephanie will call you back at the earliest opportunity.

What if something goes wrong?
If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact Sheffield Patient Services Team (previously known as PALS) on 0114 2712400. Alternatively you can write to Sheffield Teaching Hospitals NHS Foundation Trust regarding your concerns by sending a letter to the Chief Executive. All written complaints should be sent to

Sir Andrew Cash,
Chief Executive,
Sheffield Teaching Hospitals NHS Foundation Trust,
8 Beech Hill Road,
Sheffield,
S10 2SB

Alternatively you can outline your concerns by filling out an anonymous online feedback form provided by Sheffield Teaching Hospitals NHS Foundation Trust at: https://www.sth.nhs.uk/patients/patient-experience/feedback/leave-feedback.

Organisations for further support

NHS Direct
Tel: 0845 46 47
Website: www.nhsdirect.nhs.uk

Mind, the mental health charity
Tel: 0300 123 3393
Website: www.mind.org.uk

Samaritans
Tel: 08457 90 90 90
Website: www.samaritans.org

Breathing Space
Tel: 0800 83 85 87
Website: www.breathingspacescotland.co.uk

Appendix K

Consent form for controls

Sheffield Teaching Hospitals NHS
NHS Foundation Trust
Excellence as standard

The University Of Sheffield.

CONSENT FORM – Control Group Participant

Title of Project: Self-perceptions and coping with seizures

Name of Researchers: Stephanie Clegg, Dr. Fuschia Sirois, Prof Markus Reuber

	Please initial box
1. I confirm that I have read and understand the information sheet version ____ dated ____ for the above study and have had the opportunity to ask questions.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.	☐
3. I understand that data collected during the study may be looked at by members of the research team from the University of Sheffield, regulatory authorities or representatives from the NHS Trust.	☐
4. I understand that a notification will be sent to my GP if high levels of anxiety or depression are detected from my answers, which may require an offer of treatment from my GP.	☐
5. I agree to take part in the above study and understand that the data will be used as part of a Doctor of Clinical Psychology (DClinPsy) degree thesis.	☐

_____ _____ _____

Name Date Signature

GP details

GP: _____

Practice: _____

_____

Appendix L

Demographic questionnaire

Personal Information Study ID (completed by the researcher).....

Please answer the following questions about yourself. The information you are giving us will be treated as confidential and will be anonymised. Do not put your name anywhere on the questionnaire.

Date of birth .....

Gender (please tick as appropriate)

☐ Male ☐ Female

Work (Please tick as appropriate)

☐ I am at school/ college
☐ I am at university
☐ I am employed
☐ I am self-employed
☐ I am unemployed
☐ I receive disability benefits
☐ I have retired on health-grounds
☐ I receive an old age pension

For how many years were you in full time education? .....years

How do you rate your overall current health? (check one most appropriate box):

Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐

The next two questions were included in epilepsy and NEAD groups only:

What is your current diagnosis? (please tick as appropriate)

☐ Epilepsy ☐ Non-epileptic attack disorder
☐ Not sure

Are you on any medication? (please tick as appropriate)

☐ Yes ☐ No

If yes, please list your medication below:

.....
.....
.....
.....

Appendix M

Self-compassion scale-short form (SCS-SF)

Self-Compassion Scale- Short Form (SCS-SF)

HOW I TYPICALLY ACT TOWARDS MYSELF IN DIFFICULT TIMES

Please read each statement carefully before answering. To the right of each statement, indicate how often you behave in the stated manner, using the following scale:

1 ALMOST NEVER	2	3	4	5 ALMOST ALWAYS

1. When I fail at something important to me I become consumed by feelings of inadequacy.	1 2 3 4 5
2. I try to be understanding and patient towards those aspects of my personality I don't like.	1 2 3 4 5
3. When something painful happens I try to take a balanced view of the situation.	1 2 3 4 5
4. When I'm feeling down, I tend to feel like most other people are probably happier than I am.	1 2 3 4 5
5. I try to see my failings as part of the human condition.	1 2 3 4 5
6. When I'm going through a very hard time, I give myself the caring and tenderness I need.	1 2 3 4 5
7. When something upsets me I try to keep my emotions in balance.	1 2 3 4 5
8. When I fail at something that's important to me, I tend to feel alone in my failure	1 2 3 4 5
9. When I'm feeling down I tend to obsess and fixate on everything that's wrong.	1 2 3 4 5
10. When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.	1 2 3 4 5
11. I'm disapproving and judgmental about my own flaws and inadequacies.	1 2 3 4 5
12. I'm intolerant and impatient towards those aspects of my personality I don't like.	1 2 3 4 5

Appendix N

Coping efficacy scale (seizure and control groups)

Coping with your Seizures

Please indicate how well you feel you have been dealing with the different aspects of your seizures in general by checking a box for each question.

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
a) I am successfully coping with the symptoms of my seizures.					
b) I am successfully coping with the day to day problems that living with my seizures creates.					
c) I am successfully coping with the emotional aspects of my seizures.					

Amended Control Version:

Please indicate how well you feel you have been dealing with the different aspects of your life in general by checking a box for each question.

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
a) I am successfully coping in general.					
b) I am successfully coping with day to day problems that occur.					
c) I am successfully coping with the emotional aspects of my life.					

Appendix O

Gratitude questionnaire (GQ-6)

Gratitude Questionnaire GQ6

Using the scale below as a guide please circle a number beside each statement to indicate how much you agree with it.

1 Strongly Disagree	2 Disagree	3 Disagree Slightly	4 Neutral	5 Agree Slightly	6 Agree	7 Strongly Agree

1. I have so much in life to be thankful for.	1 2 3 4 5 6 7
2. If I had to list everything that I felt grateful for, it would be a very long list.	1 2 3 4 5 6 7
3. When I look at the world, I don't see much to be grateful for.	1 2 3 4 5 6 7
4. I am grateful to a wide variety of people.	1 2 3 4 5 6 7
5. As I get older, I find myself more able to appreciate the people, events, and situations that have been part of my life history.	1 2 3 4 5 6 7
6. Large amounts of time can go by before I feel grateful to something or someone.	1 2 3 4 5 6 7

Appendix P

Generalised Anxiety Disorder-7 (GAD-7)

Generalised Anxiety Disorder-7 (GAD-7)

Over the last 2 weeks, how often have you been bothered by the following problems?			
0 Not at all	1 Several days	2 Over half the days	3 Nearly every day
GAD-7			
1) Feeling nervous, anxious, or on edge			0 1 2 3
2) Not being able to stop or control worrying			0 1 2 3
3) Worrying too much about different things			0 1 2 3
4) Trouble relaxing			0 1 2 3
5) Being so restless that it's hard to sit still			0 1 2 3
6) Becoming easily annoyed or irritable			0 1 2 3
7) Feeling afraid as if something awful might happen			0 1 2 3

Appendix Q

Patient Health Questionnaire-9 (PHQ-9)

Patient Health Questionairre-9 (PHQ-9)

Over the last 2 weeks, how often have you been bothered by the following problems?			
0 Not at all	1 Several days	2 Over half the days	3 Nearly every day
PHQ-9			0 1 2 3
1) Little interest or pleasure in doing things			0 1 2 3
2) Feeling down, depressed or hopeless			0 1 2 3
3) Trouble falling asleep, or sleeping too much			0 1 2 3
4) Feeling tired or having little energy			0 1 2 3
5) Poor appetite or overeating			0 1 2 3
6) Feeling bad about yourself- or that you are a failure or have let your family down			0 1 2 3
7) Trouble concentrating on things, such as reading the newspaper or watching television			0 1 2 3
8) Moving or speaking so slowly that other people could have noticed. Or the opposite- being so fidgety and restless that you have been moving around a lot more than usual.			0 1 2 3
9) Thoughts that you would be better off dead or hurting yourself in some way.			0 1 2 3

Appendix R

European Quality of Life – 3 Dimensions Scale (EQ-5D-3L)

content removed due to copyright

content removed due to copyright

Appendix S

Short Almost Perfect Scale (SAPS)

Short almost perfect scale (SAPS)

The following statements are designed to measure attitudes people have toward themselves, their performance, and toward others. There are no right or wrong answers. Please respond to all of the statements. Use your first impression and do not spend too much time on individual statements in responding. Respond to each of the statements using the scale below to describe your degree of agreement with each statement. Circle your responses to the right of each statement.

1 STRONGLY DISAGREE	2 DISAGREE	3 SLIGHTLY DISAGREE	4 NEUTRAL	5 SLIGHTLY AGREE	6 AGREE	7 STRONGLY AGREE

1. I have high expectations for myself.	1 2 3 4 5 6 7
2. Doing my best never seems to be enough.	1 2 3 4 5 6 7
3. I set very high standards for myself.	1 2 3 4 5 6 7
4. I often feel disappointment after completing a task because I know I could have done better.	1 2 3 4 5 6 7
5. I have a strong need to strive for excellence.	1 2 3 4 5 6 7
6. My performance rarely measures up to my standards.	1 2 3 4 5 6 7
7. I expect the best from myself	1 2 3 4 5 6 7
8. I am hardly ever satisfied with my performance.	1 2 3 4 5 6 7

Appendix T

Liverpool Seizure Severity Scale – Revised (LSSS-3)

content removed due to copyright

content removed due to copyright

content removed due to copyright

Appendix U

NHS ethical approval and Health Research Authority (HRA) approval

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

Gwasanaeth Moeseg Ymchwil
Research Ethics Service

Ariennir gan Lywodraeth Cymru
Funded by Welsh Government

Wales REC 6
First Floor
Institute of Life Science 2
Swansea University
Singleton Park
Swansea
SA2 8PP

Telephone : 01792 606334
E-mail : penny.beresford@wales.nhs.uk
Website : www.hra.nhs.uk

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

01 March 2017

Professor Markus Reuber
Professor of Clinical Neurology
University of Sheffield
Academic Neurology Unit
Royal Hallamshire Hospital
Glossop Road, Sheffield
S10 2JF

Dear Professor Reuber

Study title:	**Self-perceptions and Seizures**
REC reference:	**17/WA/0043**
Protocol number:	**STH19617**
IRAS project ID:	**211497**

Thank you for responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact please contact hra.studyregistration@nhs.net outlining the reasons for your request.
Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).
Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.
There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	*Version*	*Date*
Contract/Study Agreement [Research contract - student and supervisors]	1	15 January 2017
Copies of advertisement materials for research participants [online recruitment materials]	1	15 January 2017
Costing template (commercial projects) [non-commercial costing form: agreed with university of sheffield]	1	15 January 2017
Covering letter on headed paper	1	

GP/consultant information sheets or letters [GP diagnosis confirmation]	1	15 January 2017
IRAS Application Form [IRAS_Form_26012017]		26 January 2017
IRAS Application Form XML file [IRAS_Form_26012017]		26 January 2017
IRAS Checklist XML [Checklist_26012017]		26 January 2017
IRAS Checklist XML [Checklist_28022017]		28 February 2017
Letters of invitation to participant [Invite letter- seizure clinic]	1	15 January 2017
Non-validated questionnaire [Patient questionnaire (seizures)]	1	19 January 2017
Other [PIS controls]	1	15 January 2017
Other [consent seizure online]	1	15 January 2017
Other [consent online control]	1	15 January 2017
Other [Invite letter- online seizure]	1	15 January 2017
Other [validated questionnaire GQ6]	1	19 January 2017
Other [validated questionnaire GAD-7]	1	19 January 2017
Other [validated questionnaire COPE-brief]	1	19 January 2017
Other [validated questionnaire EQ-5D-3L]	1	19 January 2017
Other [validated questionnaire SAPS]	1	19 January 2017
Other [validated questionnaire PHQ-9]	1	19 January 2017
Other [non validated questionnaire- controls questionnaire]	1	19 January 2017
Other [GP letter- high levels anxiety/depression]	1	23 January 2017
Other [PIS controls]	2	14 February 2017
Other [consent clinic control]	2	21 February 2017
Other [Invite letter- controls]	2	14 February 2017
Other [Provisional Opinion Response Letter]	1	21 February 2017
Participant consent form [Consent form- seizure clinic]	1	15 January 2017
Participant information sheet (PIS) [PIS-seizure clinic]	2	14 February 2017
Participant information sheet (PIS) [PIS seizures online]	2	14 February 2017
Referee's report or other scientific critique report [scientific approval letter]	1	30 November 2016
Research protocol or project proposal [Protocol]	1	19 January 2017
Summary CV for Chief Investigator (CI) [M.Reuber CV]	1	14 April 2015
Summary CV for student [S.Clegg CV]	1	23 January 2017
Summary CV for supervisor (student research) [F.Sirois CV]	1	23 January 2017
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Flowchart of project procedure]	1	23 January 2017
Validated questionnaire [Self compassion scale- short form]	1	19 January 2017

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators

- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance

We are pleased to welcome researchers and R & D staff at our RES Committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

17/WA/0043	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

pp
Prof Roy L. Evans
Chair

Email: penny.beresford@wales.nhs.uk

Enclosures: *"After ethical review – guidance for researchers" [SL-AR2]*

Copy to: *Mrs Samantha Walmsley, Sheffield Teaching Hospitals NHS FT*

NHS
Health Research Authority

Miss Stephanie Clegg
Clinical Psychology Unit
University of Sheffield
Cathedral Court
1 Vicar Lane,
Sheffield
S1 2LT

Email: hra.approval@nhs.net

23 March 2017

Dear Miss Clegg

Letter of HRA Approval

Study title:	**Self-perceptions and Seizures**
IRAS project ID:	**211497**
Protocol number:	**STH19617**
REC reference:	**17/WA/0043**
Sponsor	**Sheffield Teaching Hospitals NHS FT**

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

IRAS project ID	211497

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application

IRAS project ID	211497

procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

Your IRAS project ID is **211497**. Please quote this on all correspondence.

Yours sincerely

Beverley Mashegede
Assessor

Email: hra.approval@nhs.net

Copy to: Mrs Samantha Walmsley, Sponsor Contact, Lead NHS R&D Contact

Professor Markus Reuber, Chief Investigator

Appendix V

Research and development sponsorship confirmation

Ref: STH19617/SW

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

21 March 2017

Miss Stephanie Clegg
Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TP UK

Dear Stephanie

Sponsorship Confirmation

STH ref:	*STH19617*
Study title:	*Self Perceptions and Seizures*
Chief Investigator (also PI):	*Professor Markus Reuber (STH NHS FT & UoS)*

As a requirement of the Department of Health Research Governance Framework for Health and Social Care, all health related research conducted within The Sheffield Teaching Hospital NHS Foundation Trust must have a sponsor declared prior to commencement of the project.

For the above mentioned study, the sponsor shall be Sheffield Teaching Hospitals NHS Foundation Trust, as it meets the requirements outlined in section 2c of the attached Sponsorship Arrangements document.

The sponsor will take overall responsibility for this study, but can delegate one or more elements of the sponsorship to partner organisation(s).

Yours sincerely

pp

Professor Simon Heller
Director of R&D, Sheffield Teaching Hospitals NHS Foundation Trust
Telephone +44 (0) 114 2265938
Fax +44 (0) 114 2265937

V3.2

Appendix W

Letter to GP or Consultant Neurologists indicating possible depression or anxiety

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

Academic Neurology Unit,
Royal Hallamshire Hospital,
Glossop Road,
Sheffield.

DATE

SELF-PERCEPTIONS AND SEIZURES (STH 19617)

Re: DOB

Dear

Your patient consented to take part in the above internet-based research project conducted by a research team based at the Sheffield Teaching Hospitals NHS Foundation Trust and the University of Sheffield. Details of the study are provided in the enclosed Participant Information Sheet.

We are writing to inform you that the above individual scored ____ on the _____ questionnaire. This score indicates that the individual may have some symptoms related to _____. Please consider whether your patients could benefit from monitoring/ review.

Should you require any further details about this study please contact our researcher Stephanie Clegg, Clinical Psychology Unit, The University of Sheffield, Cathedral Court Floor F, 1 Vicar Lane, Sheffield, S1 2LT, sclegg2@sheffield.ac.uk.

We value your involvement in our work with your patient.

With best wishes

Yours sincerely

Professor Markus Reuber,

Honorary Consultant Neurologist (MD, PhD, FRCP).

Enc.: Patient information sheet