Title:

Self-Compassion and Adjustment in Epilepsy and Psychogenic Non-Epileptic Seizures

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Abstract

Purpose. Self-compassion has been 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. The aim of this study was to investigate whether self-compassion is associated with adjustment in people with epilepsy (PWE) and people with psychogenic non-epileptic seizures (PWPNES). Adjustment was measured via coping efficacy, quality of life (QoL), anxiety, and depression.

Method. A cross-sectional questionnaire design was employed. PWE (N = 74), PWPNES (N = 46), and controls (N = 89), recruited from outpatient seizure clinics and online, completed questionnaires about their self-compassion, coping efficacy, QoL, anxiety and depression levels.

Results. Overall, self-compassion was associated with adjustment in PWE and PWPNES. Self-compassion was negatively related to anxiety and depression in PWE, PWPNES and controls; and positively related to coping efficacy in PWE and PWPNES. Self-compassion was also positively related to QoL in PWE and controls; however, this relationship was not significant in PWPNES.

Conclusion. Self-compassion is associated with better adjustment in PWE and PWPNES. Implications of these findings for psychotherapeutic interventions for individuals with seizure disorders and future research are discussed.

Keywords: *self-compassion, epilepsy, PNES, anxiety, depression.*

Highlights

- First study to investigate the associations between self-compassion and adjustment in both people with epilepsy (PWE) and people with psychogenic non-epileptic seizures (PWPNES).

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

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

1 Introduction

Psychogenic Non-Epileptic Seizures (PNES) and Epilepsy are chronic conditions characterised by recurrent seizures. Epileptic seizures are characterised by signs and symptoms caused by abnormal electric discharges in the brain whereas seizures in PNES are not associated with abnormal electric activity. Instead PNES 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).

Epilepsy can be treated effectively with anti-epileptic drugs, but about one third of patients do not respond to medication (Duncan, Sander, Sisodiya, & Walker, 2006). In some patients medication reduces the number or severity of seizures but does not abolish them altogether. Psychological interventions are sought by some people with epilepsy (PWE) to increase their quality of life (QoL; Pinikahana, & Dono, 2009). However, evidence of the effectiveness of psychotherapy for epilepsy is still limited (Ramaratnam, Baker, & Goldstein, 2008; Michaelis et al., 2017). Ramaratnam et al. (2008) have suggested that psychotherapies for epilepsy have not been more effective because our understanding of the psychological problems faced by PWE is limited. Nevertheless, the National Institution for Health and Care Excellence (NICE) guidelines for epilepsy (2012) state that adjunctive psychological interventions (cognitive behavioural therapy, relaxation and biofeedback) should be made available for PWE.

The treatment typically recommended for people with PNES (PWPNES) is psychotherapy (Hingray et al. 2018), although evidence for the effectiveness of psychological interventions for these seizures is also limited (La France, Reuber, & Goldstein, 2013), and our understanding of the psychological mechanisms underlying PNES remains incomplete

(Brown & Reuber, 2016b). Brown and Reuber (2016a; 2016b) recently reviewed the literature on psychological and psychiatric factors associated with PNES and suggested an Integrative Cognitive Model of the disorder which can inform psychological formulation and psychotherapeutic intervention on an individual patient level. While there is still a dearth of evidence for the longer-term effectiveness of psychological interventions for PNES (Mayor, Howlett, Grunewald, & Reuber, 2010), it is well documented that long-term seizure and social outcomes are poor if no specific treatment is offered (Reuber & Elger, 2003).

Although the recommended specific interventions for PWE and PWPNES differ, research shows similarities between the presentations of individuals suffering from both conditions. Anxiety and depression are twice as common in PWE than the general population, and even more prevalent in people with PWPNES (Diprose, Sundram & Menkes, 2016; Kerr, 2012). Both seizure disorders have been associated with reduced self-esteem (Dimaro et al., 2015). Depression has been related to poor epileptic seizure control (Margrove, Menash, Thapar, & Kerr, 2011) and anxiety in PWPNES has been associated with avoidant behaviour tendencies and higher seizure frequency (Bakvis, Spinhoven, Zitman, & Roelofs, 2011; Dimaro et al., 2014). Avoidance can lead to social isolation and loss of self-confidence, which could, in turn, increase psychological distress and decrease QoL (Kerr et al., 2011). Several studies suggest that an individual's coping resources are not only relevant in patients with PNES but that they are also an important determinant of people's 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).

There is growing evidence linking self-compassion to adaptive coping and lower stress in chronic illness populations, including individuals with epilepsy (Baker, Caswell, &

Eccles, 2019). Self-compassion has been 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 demonstrated that self-compassion is linked to indicators of adjustment in individuals with chronic illness, including well-being and favourable medical outcomes (Ferrari et al., 2017) as well as adaptive coping and lower stress (Sirois, Molnar, & Hirsch, 2015). Understanding the potential of self-compassion to facilitate adaptive coping and therefore to reduce stress in individuals with epilepsy and PNES is important as stress and anxiety could be a trigger for both epileptic and psychogenic non-epileptic seizures and contribute to a reduction of QoL in either disorder (Novakova, Harris, Ponnusamy, & Reuber, 2013; Brown & Reuber, 2016a).

The current study aimed to examine the association of self-compassion with adjustment in PWE and PWPNES. Coping efficacy was considered the primary indicator of adaptive coping and adjustment. Adjustment was also assessed through anxiety and depression levels and QoL. A healthy control group was included critically to appraise whether findings are specific to PWE and PWPNES or comparable to the general population. More specifically, the study tested the following hypothesis:

1) Self-compassion levels will be lower in both patient groups (epilepsy and PNES) than in controls. Self-compassion levels with be lower in PWPNES than PWE.

2) Self-compassion will be positively correlated with coping efficacy and QoL in PWE and PWPNES.

3) Levels of self-compassion will be negatively correlated with anxiety and depression in PWE and PWPNES.

2 Method

2.1 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.

2.1.1.Epilepsy and PNES Groups

Clinic recruitment. Participants with diagnoses of epilepsy or PNES were recruited from a neurology outpatient clinic at the Royal Hallamshire Hospital, Sheffield. Patients were only included if their diagnoses of epilepsy or PNES 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 PNES were excluded. Inclusion criteria included being over 16 years of age, able to give informed consent, and complete self-report questionnaires independently or with minimal help. Participants completed the questionnaire either via hard copy or were given a link to complete the questionnaire online (see below). Of 128 participants who were approached about the study in clinic 57 returned a completed paper questionnaire pack.

Social media and online recruitment. As well as from clinics, participants were recruited from social media and websites for epilepsy and PNES self-help. Participants recruited in this way were asked to self-screen using the inclusion criteria listed above. Twenty-six participants with PNES and 37 participants with epilepsy were recruited online. General Practitioners were contacted to confirm diagnoses of online participants.

2.1.2 Control Group

Participants were recruited from a notice posted to a university volunteer's mailing list. Inclusion criteria encompassed adults who self-verified that they were 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.

2.2 Measures

All participants were asked to complete a demographic questionnaire including their age, gender, employment, education, overall current health, diagnosis and medication. The following measures were also completed:

2.2.1 Self-Compassion Scale- Short Form (SCS-SF) (Raes, Pommier, Neff, & Van Gucht, 2011). 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.

2.2.2 Coping Efficacy Scale (Gignac et al., 2000). 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.

2.2.3 Generalised Anxiety Disorder-7 (GAD-7) (Spitzer, Kroenke, Williams & Lowe, 2006). 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 10. Participants scoring 10 or above can be considered to be suffering from clinically significant anxiety symptoms (Spitzer et al. 2006). 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.

2.2.4 Patient Health-Questionnaire-9 (PHQ-9) (Kroenke, Spitzer, & Williams, 2001). 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 on a four-point scale ranging from 0 (*not at all*) to 3 (*nearly every day*). The 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., 2001). In the current study the PHQ-9 was show to have good reliability with Cronbach's alpha >.80 for all groups.

2.2.5 European Quality of Life – 3 Dimensions Scale (EQ-5D-3L) (Sanchez-Arenas et al., 2014). 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 PNES or control group. Therefore the single VAS score is used in the current study.

2.2.6 Liverpool Seizure Severity Scale – Revised (LSSS-3) (Scott-Lennox, Bryant-Comstock, Lennox, & Barker, 2001). 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. 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. The LSSS-3 has been used widely among epilepsy and PNES populations (e.g. Novakova, Harris, Rawlings & Reuber, 2019) although it was not originally designed or validated to describe PNES. The LSSS-3 was shown to have good reliability in the current study with Cronbach's alpha >.80 for both epilepsy and PNES groups.

2.3 Analytic Method

Appropriate screens were carried out for assumptions for parametric bivariate correlations and analysis of variance. Where these assumptions were not met non-parametric equivalents were carried out. To reduce the risk of false positive findings associated with multiple tests, a Bonferroni correction was applied to between-group analysis. Significance level was set at .05 for correlation analysis and correlations were characterised as weak ($p < .05$) moderate ($p < .01$) or strong ($p < .001$) (Cohen, 1988).

2.4 Power Analysis

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. In order to achieve 80% power with a sample size of 120 (40 epilepsy, 40 PNES and 40 controls) and an 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.

2.5 Ethical Considerations

Ethical approval for this study was obtained from The Wales Research Ethics Committee 6 Proportionate Review Sub-Committee.

3 Results

3.1 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. The main dependent self-compassion variable (SCS-SF) 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 PNES diagnosis.

3.2 Sample Characteristics

The complete sample consisted of 209 individuals (74 epilepsy, 46 PNES, 89 control); 152 participants were female.

3.3 Comparison Between-Groups

Statistical comparisons of demographic, seizure and psychological variables between groups are shown in Table 1.

	Epilepsy (n=74)	*PNES (n=46)*	*Controls (n=89)*	*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) (min: 12, max: 60)	34.5 ± 9.5	31.5 ± 9.3	36.8 ± 9.9	< .001**
Anxiety/ GAD-7: median (IQR) (min: 0, max: 21)	7 (11)	11 (11)	3 (6)	<.001**
Depression/ PHQ-9: median (IQR) (min: 0, max: 27)	7.5 (10)	15 (12.8)	3 (6)	<.001**
Coping efficacy: median (IQR) (min: 3, max: 15)	10.1 (5.3)	8 (7)	13 (4)	<.001**

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

Table 1: *Statistical demographic, seizure and psychological comparison between groups*

3.4 Demographics. The Kruskal-Wallis test identified a significant between group difference ($p < 0.001$) between at least one pair of groups. Dunn's pairwise tests demonstrated significant differences ($p <. 001$, adjusted using Bonferroni correction) in education levels between control and epilepsy groups, as well as between control and PNES groups.

3.5 Seizure characteristics. A Mann-Whitney U test demonstrated a significant difference ($U = 2704.5$, $p <. 001$) in seizure frequency in the last four weeks between epilepsy and PNES groups with more frequent seizures reported by PNES participants. There was no significant difference in seizure severity between the two groups.

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

3.7 Main Analyses

A one way ANOVA found significant differences in self-compassion scores between groups ($F(2,206) = 8.87$, $p <. 001$). A Bonferroni post-hoc test revealed that control participants had significantly higher levels of self-compassion ($M = 38.6$, $SD = 9.9$) than epilepsy participants ($M = 34.5$, $SD = 9.5$) or PNES participants ($M = 31.5$, $SD = 9.3$). No difference was found between the epilepsy and PNES groups. Correlational analysis results are shown in Table 2. Self-compassion was positively correlated with coping efficacy in both the epilepsy and PNES groups (moderate correlations). No relationship was found between self-compassion and coping efficacy in the control group.

The Kruskal-Wallis test found a significant difference ($p < 0.001$) in anxiety in at least one pair of groups. Dunn's pairwise tests revealed significant differences ($p < .001$, adjusted using Bonferroni correction) in anxiety levels between controls and both patient groups. No difference was found between the epilepsy and PNES groups.

The Kruskal-Wallis test demonstrated a significant difference ($p < 0.001$) in depression in at least one pair of groups. Dunn's pairwise tests revealed significant differences in depression levels ($p < .001$, adjusted using Bonferroni correction) between all three groups.

Large negative correlations were found between self-compassion and anxiety and depression in epilepsy, PNES and control groups. There was a moderate positive correlation between self-compassion and QoL in the epilepsy and control groups. No relationship was found between self-compassion and QoL in the PNES group.

	Coping efficacy	Anxiety	Depression	QoL (VAS)
Epilepsy (n=74)				
Self-compassion	.40***	-.64***	-.57***	.42***
PNES (n=46)				
Self-compassion	.37*	-.74***	-.69***	.18
Control (n=89)				
Self-compassion	.19	-.72***	-.59***	.33**

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

Table 2: *Correlational analysis of the study variables across the three groups*

4 Discussion

The aim of this study was to investigate whether self-compassion is associated with adjustment in PWE and PWPNES. Adjustment was measured via coping efficacy, anxiety, depression and QoL. Overall, self-compassion was associated with adjustment in PWE and PWPNES. Self-compassion was negatively associated with anxiety and depression in all three groups (PWE, PWPNES and controls); and positively associated with coping efficacy in PWE and PWPNES. Self-compassion was positively associated with QoL in PWE and controls; however, this relationship was not found in PWPNES. Between-group comparisons found PWE and PWPNES have lower levels of self-compassion and higher levels of anxiety compared to controls. PWPNES were found to have the highest levels of depression, followed by PWE and then controls.

The finding that self-compassion was positively associated with coping efficacy in PWE and PWPNES 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, PNES and/or other chronic illnesses, possibly because such individuals have a greater number of daily stressors to cope with. 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 & Rowse, 2017).

As chronic illnesses present regular unpredictable challenges and stressors, individuals with higher levels of self-compassion have more opportunities to utilise an adaptive set of coping strategies to manage these. Findings from the current study suggest that the unpredictable stressors and challenges presented by chronic seizure disorders may make it difficult for individuals with these disorders to be self-compassionate. Previous

research has shown that PWPNES are more likely to engage in experiential avoidance (Cullingham, Kirkby, Sellwood, & Eccles, 2019), and escape avoidant coping styles (Goldstein, Drew, Mellers, Mitchell-O'Malley, & Oakley, 2000; Dimaro et al., 2014). The current findings suggest moving away from avoidance and becoming more self-compassionate to an individual's seizure experiences may increase coping efficacy.

Our findings match those of previous studies which show that the presence of stress in other chronic illnesses (e.g. arthritis) is associated with low self-compassion (Sirois & Rowse, 2017; Sirois et al., 2015). Our correlational findings also match those from previous studies in patients with other chronic disorders. For example, coping efficacy has been linked to better adjustment in other chronic illness populations including arthritis (Gignac et al., 2000) and inflammatory bowel disease (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, including epilepsy (MacBeth & Gumley, 2012; Gignac et al., 2000; Brion, Leary, & Drabkin, 2014; Pinto-Gouveia, Duarte, Matos & Fraguas 2014; Baker et al., 2019).

Findings are in agreement with previous research suggesting anxiety and depression are more common in PWE and PWPNES than the general population (Kerr, 2012) and that depression levels are especially high in PWPNES (Walsh, Levita & Reuber, 2018). The study did not 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 and found that anxiety levels were usually moderately elevated in PWE and PWPNES. Therefore high anxiety may be associated with living with a seizure disorder per se rather than PNES specifically. Alternatively, increased anxiety levels in PNES may not have been captured well by the self-report instrument used in this study as previous research indicates that levels of alexithymia tend to be higher in PWPNES than those with epilepsy

(Brown & Reuber, 2016b). Therefore 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 PWPNES. This is in contrast with previous research suggesting high level of self-compassion is linked to 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 rather than a disease-specific 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).

4.1 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. 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. While efforts were made to confirm participant's PNES 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 many PWPNES 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 the generalisability of our 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. Furthermore no data was gathered regarding how long participants had their seizure disorder. Therefore no investigations were carried out into whether the duration of the disorder and coping efficacy or self-compassion are related.

A strength of the study was the inclusion of a control group to appraise whether findings are specific to PWE and PWPNES or comparable to the general population. The inclusivity of the recruitment method, encompassing both clinic and online epilepsy and PNES 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 and the number of PWPNES recruited exceeded group sizes in similar studies recently published within the PNES literature (Karakis et al., 2014; La France et al., 2011).

4.2 Future Directions

A number of studies now show that self-compassion can be cultivated (e.g., Boellinghaus, Jones, & Hutton, 2014). Research into the effectiveness of cultivating self-compassion in different ways with PWE and PWPNES, and the effect of this on coping with the disorders should be investigated. Future research may also benefit from comparing individuals with well controlled vs. poorly controlled seizure disorders, and from ascertaining

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 PWPNES would be beneficial. Investigating health related QoL or breaking down QoL into subsets and investigating the relationship of these with self-compassion in the PWE and PWPNES may further understanding of this relationship.

4.3 Clinical Implications

The findings from this study suggest self-compassion is associated with with QoL, lower anxiety and depression in PWE; and lower anxiety and depression in PWPNES. 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. 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 based interventions to test acceptability and efficacy in the epilepsy and PNES populations will be important.

5 Conclusion

The current study is the first to investigate the associations between self-compassion and adjustment in both PWE and PWPNES. Overall, self-compassion was shown to be associated with better adjustment in PWE and PWPNES. Offering psychotherapies focussing on the development of self-compassion may decrease distress and increase an individual's ability to cope with and adjust to their condition. Research into the efficacy of these interventions in PWE and PWEPNES is recommended, as none currently exists.

6 References

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, D., Caswell, H., & Eccles, F. (2019). Self-compassion and depression, anxiety, and resilience in adults with epilepsy. *Epilepsy and Behaviour, 90,* 154-161. https://doi.ord/10.1016/j.yebeh.2018.11.025

Baker, G.A., Smith, D.F., Jacoby, A., Hayes, J.A., & Chadwick, D.W. (1998). Liverpool Seizure Severity Scale Revisited. *Seizure, 7*, 201-205. doi: 10.1016/0920-1211(91)90071-M

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

Boellinghaus, I., Jones, F., & Hutton, J. (2014). The Role of Mindfulness and Loving-Kindness Mediation in Cultivating Self-Compassion and Other-Focused Concern in Health Care Professionals. *Mindfulness, 5,* 129-138. doi:10.1007/s12671-012-0158-6

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

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences*, 2nd ed. Hillsdale, NJ: Erlbaum.

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

Cullingham, T., Kirkby, A., Sellwood, W., & Eccles, F. (2019). Avoidance in nonepileptic attack disorder: A systematic review and meta-analyses. *Epilepsy & Behavior, 95,* 100-111. https://doi.org/10.1016/j.yebeh.2019.03.004

Diprose, W., Sundram, F., Menkes, D. (2016). Psychiatric comorbidity in psychogenic nonepileptic seizures compared with epilepsy. *Epilepsy & Behavior, 56,* 123-30. doi: 10.1016/j.yebeh.2015.12.037.

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

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

Ferrari, M., Dal Cin, M., & Steele, M. (2017). Self-compassion is associated with optimum self-care behaviour, medical outcomes and psychological well-being in a cross-sectional sample of adults with diabetes. *Diabetic Medicine, 34*, 1–8. https://doi.org/10.1111/dme.13451

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

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. Retrieved from http://bjgp.org/content/57/541/650.full

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

Goldstein, L. H., Drew, C., Mellers, J., Mitchell-O'Malley, S., & Oakley, D. (2000). Dissociation, hypnotizability, coping styles and health locus of control: characteristics of pseudoseizure patients. *Seizure, 9,* 314-322. https://doi.org/10.1053/seiz.2000.0421

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

Hingray, C., El-Hage, W., Duncan, R., Gigineishvili, D., Kanemoto, K., LaFrance, W. C., Jr…….. Reuber, M. (2018). Access to diagnostic and therapeutic facilities for psychogenic nonepileptic seizures: An international survey by the ILAE PNES Task Force. *Epilepsia. 59*, 203-14. https://doi.org/10.1111/epi.13952 Cited by: 10

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

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

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

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

Mayor, R., Howlett, S., Grunewald, R., & Reuber, M. (2010). Long-term outcome of brief augmented psychodynamic interpersonal therapy for psychogenic nonepileptic seizures: seizure control and healthcare utilization. *Epilepsia. 51*, 1169-76. doi: 10.1111/j.1528-1167.2010.02656.x.

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

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

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

Novakova, B., Harris, P., Rawlings, G., & Reuber, M. (2019). Coping with Stress: A pilot study of a self-help stress management intervention for patients with epileptic or psychogenic non-epileptic seizures. *Epilepsy & Behavior, 94,* 169-177. doi: 10.1016/j.yebeh.2019.03.002.

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

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

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

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., 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. (2017). 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

Spitzer, R., Kroenke, K., Williams, J., Lowe, B. (2006). A brief measure for assessing general anxiety disorder: the GAD-7. *Archives of Internal Medicine, 166,* 1092-1097. Doi: 10.1001/archinte.166.10.1092

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

Walsh, S., Levita, L., & Reuber, M. (2018). Comorbid depression and associated factors in PNES versus epilepsy: Systematic review and meta-analysis. *Seizure. In Press.*