UNIVERSITY OF HULL

The Role of Compassion in the Psychological Impact of Functional Seizures

being a thesis submitted in partial fulfilment of the

requirements for the degree of

Doctor of Clinical Psychology

in the University of Hull

by

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June 2023

Acknowledgements

First and foremost, I would like to thank, and dedicate, this paper to all 245 individuals with functional seizures who participated in this study. Without your interest, and passion to better the treatment and support options available for FND, this project would not have as much meaning as it does. To FND Dimensions, FND Hope and FND Action, I will be forever grateful for your willingness to share and advertise the study multiple times, allowing me to present my research ideas at conferences and connect with others with similar experiences to my own. This research has allowed me to feel a sense of community with a condition that once felt so isolating, and that is because of you.

Philip and Tim- your wisdom, words of comfort and continuous support has gotten me through the highs and lows of this project. I would not have gotten to this point without either of you.

Similarly, thank you to all placement supervisors, especially Emily Thornhill, and Mary Walker, who have both continuously provided warmth, support and encouragement throughout the stressors of the previous year.

Finally, to my partner Joseph who has stuck with me and gotten me through the turbulent time of the doctorate.

Overview

This thesis portfolio comprises three parts:

Part One: Systematic Literature Review

The systematic literature review aimed to synthesise the evidence base of cognitive-behavioural therapy (CBT) and third-wave approaches to assess their effectiveness in alleviating psychological distress in people living with functional seizures (PwFS). Following a search using five electronic databases, seventeen papers were identified to meet the inclusion criteria and were quality assessed using the Effective Public Health Practice Project assessment tool. The papers were reviewed using a narrative synthesis approach. Reviewed interventions included individual, group and inpatient CBT, prolonged exposure, acceptance and commitment therapy and mindfulness-based therapy. Findings differed, based on study quality, methods and results although favourable evidence was provided for individual CBT. Promising evidence for several remaining interventions was discussed. The review concluded that psychological intervention is more beneficial for those with increased distress at baseline, and individualised treatment based on patient need and seizure aetiology may be a more beneficial approach. Clinical and future research implications are discussed.

Part Two: Empirical Paper

The empirical paper aimed to measure whether the flow of compassion (compassion to self, compassion from others, compassion to others) moderated the relationship between functional seizure severity (SS) and their psychological impact. 245 individuals with a diagnosis of FS completed an online survey comprising of SS, flow of compassion, anxiety, depression and stress, mental wellbeing and quality of life (QoL) measures. Correlational and regression analyses were conducted to test variables' relationships and to establish whether the flow of compassion had a moderating effect. The study found compassion to self moderated the relationship between

seizure severity and mental wellbeing. Further predictive relationships were established and discussed. Clinical and future research implications were considered.

Part Three comprises the Appendices

The appendices relate to the systematic literature review and empirical paper. Reflective and epistemological statements are included.

Total word count: 12,069

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Part 1

Part 2

Cognitive-Behavioural and Third-Wave Interventions for Alleviating Psychological Distress in Functional Seizures: A Systematic Review

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This paper is written in the format ready for submission to the Seizure: The European Journal of Epilepsy. Please see Appendix C for the Guideline for Author Guidelines

Word Count: 7,178

Abstract

Purpose: Functional seizures are seizures that may resemble epileptic seizures but are not caused by abnormal brain activity. The aetiopathogenesis of functional seizures is complex and individual to each person and has high comorbidity rates with psychological difficulties, exacerbated by living with the condition. Cognitive behavioural therapy (CBT) is recommended for managing psychological difficulties in chronic health conditions; however, the evidence base for third-wave approaches is also increasing. The aim of this review was to synthesise the evidence base of these approaches to assesses their effectiveness in alleviating psychological distress in people living with functional seizures (PwFS).

Methods: A search was conducted using electronic databases: PsycINFO, PsycARTICLES, CINAHL Complete, MEDLINE and Academic Search Premier. Seventeen papers published between 2002 and 2022 met the inclusion criteria and were assessed using a quality appraisal tool. A narrative synthesis approach was adopted.

Results: Interventions included individual, group and inpatient CBT, prolonged exposure (PE), acceptance and commitment therapy (ACT) and mindfulness-based therapy (MBT). Studies differed regarding their quality, methods, and findings and favourable evidence was provided for individual CBT, based on validity and reliability of results. Promising evidence was also identified for the remaining models.

Conclusion: Although varied, the findings for the effectiveness of CBT and third-wave interventions for alleviating the psychological impact of functional seizures is promising and seems to be more beneficial for patients with more significant mental health difficulties at baseline. However, considering the complex, individualised aetiology of FS, treatment dependent on patient need may be more helpful.

Keywords: systematic literature review, functional seizures, psychological, third-wave, CBT

1. Introduction

1.1. Definition of Functional Seizures

Functional seizures (FS), also known as non-epileptic seizures (NES), non-epileptic attack disorder (NEAD), psychogenic non-epileptic seizures (PNES) or dissociative seizures [1] are seizures that resemble epileptic seizures, sharing presentations such as paroxysmal changes in responsiveness, behaviour, and movement [2] but are not caused by abnormal brain activity [3] [4]. Due to these similarities, many people are misdiagnosed with epilepsy and it can take several years of prescribed antiepileptic drugs (AEDs), which do not treat the condition, before an accurate diagnosis is provided [5] [6]. Due to the difficulties in reaching a diagnosis based on observable features, the 'gold standard' of accurately diagnosing FS is video-electroencephalogram (vEEG) and thorough history-taking [5] [7]. There remains no certain pathophysiological cause of FS, although the current understanding is evolving from a purely psychogenic perspective and is instead moving toward one that is multifaceted and individualised. It is suggested that interactions between biopsychosocial, cognitive, and neurological risk factors and alterations in neuropathophysiological mechanisms contribute to the source and perpetuation of FS; a complex aetiopathogenesis, with risk factors individual to each patient [4]. To date, FS have an estimated prevalence of between 2-33 per 100,000 [8] [9] and make up 30% of epilepsy referrals [10], suggesting FS to be a significantly common neurological condition.

1.2. Functional seizures and psychological distress

Although the current understanding of the aetiology of FS is moving away from an absolute psychological perspective [4], the evidence-base indicates high comorbidity rates between FS and psychological difficulties such as low mood (8.9-85%), anxiety (4.5-70%), and posttraumatic stress

(7-100%) [11]. However, it is important to note that these mechanisms and aetiology do not account for all individuals with FS.

The cause-and-effect relationship between psychological difficulties and FS is ambiguous, as being diagnosed with, and living with FS also has a psychological impact, inducing anxiety and low mood [12]. Invalidation and confusion can be experienced throughout the diagnostic process, with some medical professionals alleging symptoms to be malingering or assuming a psychological cause [13] [14] [15] [16] leading to a threatened self-image [17], significant distress, anger, disappointment, and shame [13]. Some individuals experience suicidal ideation following similar negative experiences in relation to receiving a diagnosis [15] [18].

Negative interactions with medical professionals have been demonstrated to continue past diagnosis, [19], leaving people to feel disregarded, neglected [20] and angry toward professionals, leading to disengagement from further treatment [19] [20] [21]. Individuals have reported feeling embarrassed and scared about what other people may think of their condition [18] [19], leading to social exclusion as a form of avoidance coping [19] [22]. As such, patients have experienced numerous losses in their life, including freedom and independence following losing their ability to work, drive and go on holiday, provoking feelings of grief [12] [21]. These consequences of living with FS can lead to significant stress levels which are difficult to manage and may also maintain symptom triggers [12] [22].

1.3. Interventions for functional seizures

Despite the high prevalence of FS and their clear relationship with psychological difficulties, there remains no clear treatment guidance. The National Institute for Health and Care Excellence (NICE) provide evidence-based guidelines for health and social care professionals in England, recommending advisable care for individuals with specific conditions [23]. NICE currently

recommend a neurological assessment if FS are suspected [24], however, this is where guidance ceases. This continues to cause significant problems as there remains no clear guideline on which professional should be responsible for different aspects of patient care, what treatment should be offered and how to label the condition [25]. A limited number of patients are referred for treatment following diagnosis [26] and without treatment FS will usually not improve [27]. Health professionals are recognising the impact of the lack of guidance on their practice with 95% percent of medical professionals, including neurologists, paediatricians, nurses, and psychologists continuing to support the necessity for clear guidance, 75% believing this would reduce the financial cost for health care and social care in the UK [25].

Despite a multidisciplinary approach being preferable [28] [29] [30], the literature around treatment for FS predominantly comprises of psychological therapy [31], although it has been suggested occupational therapists, physiotherapists and rehabilitation experts may be able to reduce the severity of the condition [29] and provide more complex care should an individual present with other functional disorders [30]. A systematic review of 228 participants has demonstrated 47% of individuals becoming seizure-free and 82% experiencing seizure reduction of at least 50% following psychological intervention, though it did not confirm which psychological model was most beneficial [32]. However, considering the interrelationship between psychological difficulties and FS discussed previously, it is worth investigating the effectiveness of interventions in mitigating FS's psychological processes. This rationale is supported by decreased health-related quality of life (HRQoL) identified in patients with FS compared to those with epilepsy [33] [34] [35], predicted by low mood and anxiety [33] [34] [36] [37], as well as other psychological processes of coping strategies and family dysfunction [36]. These findings have led to a recommendation of interventions aiming to treat the distress associated with FS rather than solely target the seizures [36]. To date, only one review [38] has been conducted evaluating the effectiveness of

psychological interventions for wellbeing, exploring the impact on psychosocial management of FS. This review demonstrated the efficacy of CBT and psychodynamic approaches, the only models tested using a controlled design. Although, this review used a narrative method without systematic approach to study selection and quality assessment.

1.4. Functional seizures and cognitive behavioural and third-wave approaches

CBT is currently the advised psychological intervention approach for the management of depression in the general population and for those with a chronic health condition [39] [40] and has been demonstrated effective in many trials and meta-analyses in comparison to effective medications [41]. Third-wave approaches, such as acceptance and commitment therapy (ACT), are an extension of the cognitive behavioural understanding of human distress, exploring the individual's relationship to, and interpretation of, their experiences [41] [42]. Third-wave approaches have been demonstrated to be equally as effective as other psychological approaches [43] [44] and more so than treatment-as-usual [45], and efficacy has also been identified for long-term neurological conditions [46]. However, there is currently no review exploring the efficacy of CBT and third wave approaches for FS.

1.5. Rationale

Psychological difficulties are prominent in FS, either as risk factors, or impacts of living with the condition. A previous review demonstrated the effectiveness of psychological interventions in improving seizure frequency [32], without identifying the benefits of a specific model. However, it has been recommended that interventions instead focus on alleviating the psychological component of FS rather than only targeting seizure outcomes [36]. CBT is currently the most advised psychological intervention for managing psychological difficulties including low mood in a

chronic health condition [40] and in recent years, the evidence of efficacy of third-wave approaches has increased, including for long-term neurological conditions [46]. As one specific model has not yet been identified as beneficial for supporting people with FS (PwFS), it is therefore timely to continue building on the previous review exploring intervention effectiveness for psychological wellbeing in FS [38] and synthesise the literature of both CBT and third-wave approaches. The aim of the current systematic review is to the review the effectiveness of these interventions in alleviating psychological distress in PwFS.

1.6. Research Question

What is the effectiveness of cognitive behavioural and third-wave interventions for alleviating psychological distress in PwFS?

2. Method

2.1. Data sources

Databases selected for review were PsycINFO, PsycARTICLES, CINAHL Complete, MEDLINE and Academic Search Premier, accessed via the EBSCOhost service. Searches were also conducted using reference lists from selected papers to ensure all relevant studies were reviewed. Grey literature was not utilised in this review due to focus on empirical papers and necessity of these being peer-reviewed. Inclusion and exclusion criteria for the search is demonstrated in Tables 1 and 2.

Table 1: Study inclusion criteria and rationale

Inclusion	**Rationale**
Published in English	To ensure accurate interpretation

Participants 18+	Different psychological impact of seizures and available interventions for children [47] [48] [49].
Peer reviewed	Increased quality
Published 2002-2022	Focus placed on previous 20 years of research, based on first publication of paper that systematically measured effectiveness of CBT for FS [50].
International studies	To allow consideration of cultural context

Table 2: Study exclusion criteria and rationale

Exclusion	Rationale
Not empirical papers (e.g.- discussion papers, commentaries, protocols, author responses and other reviews)	To measure intervention effectiveness, inferences should be drawn from primary, concrete evidence
Papers not evaluating a psychological intervention	Medical interventions did not answer the research question of effectiveness of psychological interventions
Papers not including a mental health outcome measure	Research question focus on psychological outcomes
Case studies	Although they provide rich data, studies with one person cannot be generalised to the wider population.

Papers not focused on functional seizures	Research question focus on functional seizures particularly, rather than functional neurological disorder or epilepsy
Papers not measuring patient outcome	Papers measuring other outcomes (e.g.- professional perceptions, employment statues, cost efficacy, healthcare outcomes) do not answer the research question
Papers not utilising a CBT or third-wave approach	Review aims to explore the effectiveness of CBT and third-wave interventions

2.2. Search strategy

All known current terms, or their abbreviations, for functional seizures were used in the search conducted in summer 2022. Despite this review focusing on psychological outcomes, the search strategy did not include relative terms such as 'adjust*' or 'impact*' as this restricted potential papers, as most studies utilised mental health measures as part of their secondary outcomes, so were not included in titles.

("nonepileptic seizure*" OR "functional seizure*" OR "dissociative seizure*" OR NEAD OR PNES OR pseudoseizure*)

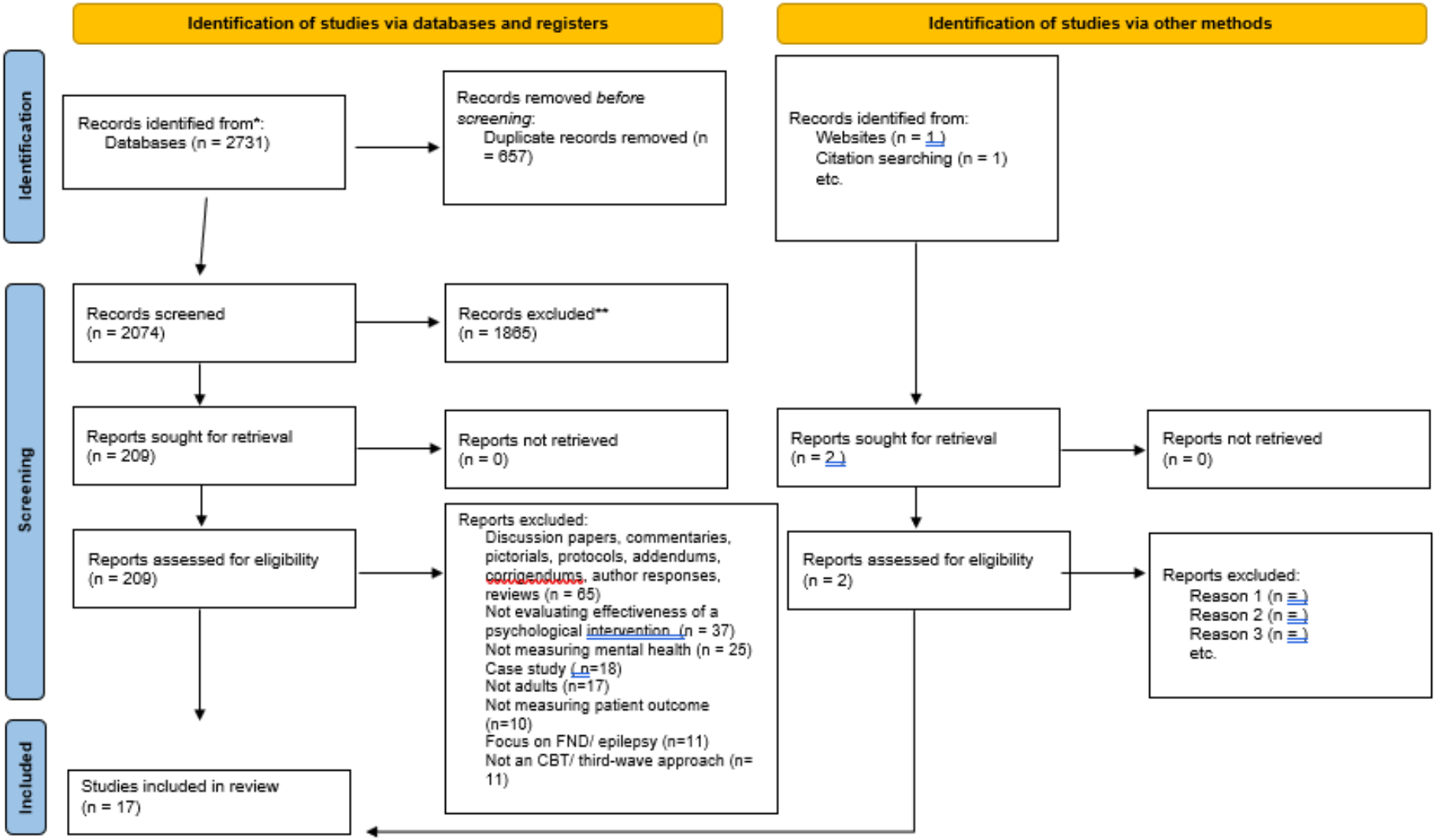
AND

(Interv* OR Therap* OR Psychotherap* OR counsel*)

An electronic search was conducted with language and date parameters applied, resulting in a total of 2731 studies. Following removal of duplicates, 2074 studies were screened for relevancy, excluding 1865 papers. An abstract screen, and full text screen for more relevant papers based on inclusion and exclusion criteria, was then conducted on 209 studies. An additional citation and

hand search was conducted, resulting in a further two studies. In total, 17 studies were included in the review. Figure 1 outlines the study selection process.

Figure 1: PRISMA flow diagram of study selection [51]



2.3. Data extraction

A data extraction form (see Appendix D) was used to synthesise information from each article. This form was created by the reviewer considering the relevant information needed to answer the research question, including study, participant, intervention, trial and outcome characteristics.

2.4. Quality Assessment

The Effective Public Health Practice Project quality assessment tool for quantitative studies [52] was utilised. This tool was developed for the assessment of public health interventions and has been deemed a reliable assessment of quantitative studies [53]. Studies receive a score of 'strong', 'moderate' and 'weak' in categories including design, selection bias and data collection. To ensure accurate implementation, the tool's associated 'dictionary' was utilised to guide the quality assessment. Nine papers were chosen at random for quality assessment by a blind second rater to ensure inter-rater reliability. There were discrepancies on one paper, which were discussed until agreement was reached. Studies that were considered to have weaker quality were not excluded from the review due to their relevance to the research question. Final quality assessment ratings are provided in Table 3. See Appendix E for quality checklist.

2.5. Data Analysis

Due to heterogeneity in study methodology, findings and quality ratings, a narrative synthesis approach was adopted, in accordance with Popay et al.'s [54] framework. The framework consists of four steps to narrative synthesis: (1) developing a theoretical model. Here, the research question was developed by considering findings of previous reviews and the applicability of these, assessing for whom the intervention helps, why and how. (2) Developing a preliminary synthesis was initially completed by recording a sentence summarising each paper considered for review. Once papers were selected using the inclusion and exclusion criteria, data extraction and quality

assessment were conducted jointly using a tabulation method to organise study methods and findings. (3) Exploring relationships in the data naturally continued from the previous step, where studies were grouped together as per their intervention model, chronology and findings. (4) assessing the robustness of the product was completed toward the end of the process, where the rigour of the synthesis was assessed and conclusions were drawn using critical reflection.

3. Results

3.1. Overview of included studies

A summary of study and participant characteristics is provided in Table 3 and trial and intervention characteristics and outcomes are summarised in Table 4. All but three studies [55] [56] [57] were conducted in the UK and USA. Studies were published between 2004- 2022. Eleven [50] [54] [58] [59] [60] [61] [62] [63] [64] [65] [66] of 17 studies confirmed diagnosis via vEEG. Most studies recruited opportunistically through outpatients and other epilepsy services, usually referred by medical professionals such as neurologists. One study recruited via social media [67]. Most studies reported participants' comorbid psychological difficulties such as depression, anxiety and PTSD and health difficulties, such as traumatic brain injury and pain. Three studies were randomized controlled trials [61] [62] [63], one was a controlled clinical trial [55]. A range of interventions were analysed in the review, including mindfulness-based therapy (MBT; n=2); individual (N = 8), group (N = 3) and inpatient-based (N=2) cognitive behavioral therapy (CBT), acceptance and commitment therapy (N=1) and prolonged exposure (N = 1).

Table 3: Study and participant characteristics and quality assessment ratings

Study (Authors; Year; Country)	Design	Participant characteristics (Sample size, mean age and gender)	Diagnosis confirmation; length of time since onset/diagnosis	Other comorbidities (physical, neurological, psychological)	Recruitment	Quality score
Bajaj et al. [55] (2017; India)	Case control	n= 50 + 20 waiting list controls 18-55 years, gender not reported	vEEG; Not reported	Not reported although participants reporting suicidality, previous psychological treatment, major psychiatric disorders (e.g.- psychosis) and co-existing neurological conditions excluded	Diagnosis confirmed by neurologist	Weak
Barret-Naylor et al. [67] (2018; UK)	Case-series	N= 6 24-69 years; 5f	No confirmation; 2-6 years from diagnosis	depression & PTSD (n=1) 1 reported anxiety (n=1), anxiety & depression (n=1)	Social media support groups	Weak
Baslet et al. [58](2015; USA)	Case series	N= 6; 18-59 years; 100% F	5 x vEEG, 1x EEG; Not reported	Frontal lobe epilepsy (n=1), headaches (n=2), sleep apnea (n=1), psychiatric diagnoses include MDD, PaD, GAD, OCPD	Medical center	Weak
Baslet et al. [59] (2020; USA)	Case series	N = 26 (completers) 46.4 (mean age); 100% F	vEEG, 1 EEG; Not reported	Depression (n=21); anxiety (n=23); PTSD (n=14); psychosis (n=4); eating disorder (n=3) TBI (n = 16); headaches (n=18), pain (n=16)	Women's hospital	Weak

Conwill et al. [68] (2014; UK)	Case series	N = 10 (nonepileptic attack group), 33.1 (mean age); 7F	EEG; 50% >5 years; 50% < 5 years since onset	Depression (n=2), anxiety (n=2), nonpsychiatric comorbidity (n =6)	Neuropsychiatry outpatients	Moderate
Cope et al. [69] (2017; UK)	Case series	N= 25, 19 completers 5 18-25 8 26-35 8 36-45 4 46+; 21 F	Neurology; 7.1 years duration	Epilepsy (n=9), no psychiatric comorbidity reported	Outpatients	Strong
Goldstein et al. [50] (2004; UK)	Case series	N = 20, 16 completers; 34.9 (mean age); 14F CBT: SMC	vEEG & EEG; 42.31 (42.41) months of onset	Psychiatric diagnoses (n=3)	Neuropsychiatry unit	Strong
Goldstein et al. [60] (2010; UK)	Pilot RCT	N=33: N= 31 37.4: 35.9 (mean age) 24: 26 (F)	vEEG/ ictal EEG/ agreement by referrers and consultants CBT- 6.3 years SMC- 5.1 years (Since onset)	Psychiatric diagnoses: 16: 15	Neuropsychiatry	Strong
Goldstein et al. [61] (2020: UK)	Parallel-group,	N = 368; 37.5 (mean age); 266F	vEEG or clinical consensus; 6.2	Comorbid medical conditions (N= 261)	27 UK neurology/epilepsy services	Strong

	multicentre RCT		years since onset			
Kuyk et al. [56] (2008; Netherlands)	Case series	N= 26; 30.6 (mean age); 77.3% F	EEG/ video registration; 6.7y since onset	Not reported	Treatment program offered in a special unit of the Epilepsy Institute	Moderate
Labudda et al. [57] (2020; Germany)	Case series	N = 80; 33.78 (mean age); 60F	Ictal EEG or confirmed by clinician; not reported	Anxiety (n = 27); Affective disorder (n = 41); personality disorder (n = 27) Comorbid epilepsy (n = 23)	Treatment offered in inpatient psychotherapy ward	Strong
LaFrance Jr. et al. [62] (2009; USA)	Case series	N = 21; 36 (mean age); 17F	vEEG; Not reported	Mood disorders (n = 14); anxiety (n = 11); impulsivity (n =1); OCPD (n = 6); somatoform disorders (n=3) History of head injury (n=7)	Neuropsychiatry	Strong
LaFrance Jr. et al [63] (2014; USA)	Pilot RCT	N= 34; CBT-ip- 37.9; 7F CBT-ip w/ sertraline- 39.1; 9F Sertraline- 39.7; 8F TAU- 41.6; 7F	vEEG; Not reported	CBT-ip: Mood disorders (n=7); anxiety (n= 6); somatoform (n=1); impulsivity (n=1); head injury (n=3) CBT-ip & sertraline: mood (n = 7); anxiety (n = 7), somatoform (n=3), impulsivity (n=1), OCPD (n =2); head injury (n=5) Sertraline:	Not reported	Strong

				Mood (n = 9); anxiety (n= 7), somatoform (n =2), impulsivity (n =3) OCPD (n=2); head injury (n=6) TAU: Mood (n =4); Anxiety (n = 7);somatoform (n = 3); impulsivity (n =2; OCPD (n = 4); head injury (n = 7)		
LaFrance Jr. et al. [64] (2020; USA)	Case series	N = 27; 49.1 (mean age); 5F	vEEG; 9.91y since onset	PTSD (n = 19); Anxiety (n = 30); Mood (n = 26); Somatoform (n = 31) Substance abuse disorder (n = 17) Cognitive disorder NOS (n = 29); TBI (n = 26)	Neuropsychiatry	Moderate
Myers et al. [65] (2017; USA)	Case series	N = 16; 42.81 (mean age) ;13F	vEEG; Diagnosed for 92.31 months	All patients diagnosed with PTSD	Not reported	Moderate
Streltzov et al. [66] (2022, USA)	Case series	N = 6; 36.2 (mean age); 100% F	vEEG; Not reported	Not reported	From epilepsy centre or other institutions	Weak
Tilahun,et al. [67] (2021, USA)	Case series	N = 160; 118f (age not reported)	Not reported	Not reported	Single tertiary care epilepsy centre outpatients	Weak

Table 4: Intervention and trial characteristics and outcomes

	Intervention	Intervention characteristics (length, setting, deliverer)	Control	Outcome measures (mental health and seizure frequency)	Timepoints	Analyses	Main findings
Bajaj et al., 2017 [55]	Individual CBT	12 1x week	Randomised waiting control group (WC) receiving standard medical treatment of anti-anxiety and anti-depressant medication	Self-reported monthly seizure frequency; HADRS	Baseline, posttreatment	Descriptive statistics and t-tests	CBT Group: Seizure frequency: reduction of 5.26(SD 2.25) to .90 (SD 1.12), very significant Anxiety: reduction of 8.10 (SD 2.25) to 4.30 (SD 4.10), very significant Depression: Reduction of 7.40 (SD 4.39) to 4.62 (SD 1.87), significant P not reported Control group not significant on any outcome
Barret-Naylor et al. , 2018 67]	ACT self-help	Participants provided chapters from 'Get Out Of Your Mind and Into Your Head' with a 30 minute telephone check-in with psychologist 1x week over a 6 week period.	No control	Self-reported weekly seizures; DASS-21	Pre and post treatment, 1-week follow-up and 1-month follow-up	Reliable change indices (RCI) & clinically significant change (CSC)	4/6 had a notable reduction in seizure frequency (no RCI or CSC criteria applied due to no outcome measure). 4/6 RCI and CSC improvement on DASS-21. After 1 month, 1 participant did not meet CSC criteria, and 1 did not meet RCI.

Baslet et al., 2015 [58]	Individual MBT	12 1x weekly/biweekly session	No control	Self-reported weekly seizures; DASS-21 & BDI-II	6th session; posttreatment	Descriptive statistics	Seizures: Reduction of 18 (baseline)- 2.25 (6th session)-2.67(12th session) (SD not reported) Depression: 4/6 had a reduction in scores (considering not all time points were collected) Anxiety: 2/6 had a reduction in scores, 2/6 had an increase
Baslet et al., 2020 [59]	Individual MBT	12 1x weekly provided by clinical social workers	No control	Self-reported weekly seizures; BDI & DASS	Diagnosis and end of treatment	Median regression analysis for seizure frequency; Linear mixed-effect models for secondary measures	Seizures: reduced by 0.12 episodes per week (p = .002) BDI: reduction of 13.8 (9.3) to -2.12 (11.9) p>.05 DASS: reduction of 9.4 (6.3) -8.96 (9.8) p>.05
Conwill et al., 2014 [68]	Group CBT	4 1hr, weekly sessions delivered by liaison nurse and OT	No control	CGI scale; monthly seizure frequency; HADS	Pre and post intervention	Paired sample t-test or Wilcoxon signed test	Depression: reduction of 10.8 (4.8)- 8.8 (5.3) p>.05 Anxiety: reduction of 9.4 (5.7)- 8.8 (5.3) p>.05
Cope et al., 2017 [69]	CBT-based psychoeducation groups	3 90 min, weekly sessions First session, lecture-based delivered by neuropsychiatrist and clinical	No control	Self-reported seizure frequency over past 4 weeks and frequency of A&E attendances;	Pre and post intervention	Descriptive statistics; ANOVA	Seizures: Pre-treatment 11.1% of patients were seizure-free; increased to 38.9% post-treatment ET7: 38.94 (18.95)- 31.70 (18.25) p = 0.028 PHQ: 13.69 (8.43)- 11.74 (6.79) p>.05

		psychologist then remainder clinical psychologist		ET7; PHQ-9; GAD-7			GAD-7: 12.32 (6.10)- 10.96 (6.05) p>.05
Goldstein et al., 2004 [50]	Individual CBT	12 1hr, weekly/fortnightly sessions delivered by trained CBT therapist	No control	Monthly seizure frequency; HADS; Fear Questionnaire	Pre and post intervention, 6-month follow-up	Wilcoxon Matched Pairs Signed Rank Tests	Seizures: pre-treatment- 18.22 (43.70)-postreatment-2.88 (4.73)- 6th month follow-up 2.59 (4.14) (p = 0.01) Anxiety: 10.06 (5.62)- 7.81 (5.52)- 8.13 (6.71) z =-2.539 (p = 0.05) Depression: 6.75 (3.55)- 4.63 (4.22)- 4.63 (5.08) z= -2.337 (p = 0.05)
Goldstein et al., 2010 [60]	Individual CBT	12 1hr sessions weekly/fortnightly CBT, delivered by trained nurse therapist	Randomised standard medical care (SMC) group (ongoing clinical review with neuropsychiatrist and, withdrawal of AEDS)	Self-reported monthly seizure diary; HADS	Pre and post intervention, 6-month follow-up	Seizures: Poisson mixed models HADS: linear mixed models	Seizures: (median) pretreatment- 12.0 (22.50)-posttreatment-2.0 (6.00)- 6th-month follow-up 1.5 (8.00) Between-groups effect size: 0.75 posttreatment; 0.42 follow-up Anxiety: 8.83 (4.95)-7.93 (3.58)-7.15 (5.16) Depression 6.74 (4.05)-6.20 (4.08)-5.69 (5.34) No group x time interactions and no main effects
Goldstein et al., 2020 [61]	Individual CBT	12 1hr sessions over 4-5 month period plus 1 booster	Randomised standard medical care (SMC) group	Monthly seizure frequency; 2 items from SSS for seizure	Pre intervention, 6- month and 12-month follow-up	Generalised linear mixed modelling	Seizures (median) Pretreatment- 12.5 (4.41; 0-535)-posttreatment 6 (3.48; 0-640)- 6th month-follow-up- 7 (1-35; 0-994)

		session 9 months following		severity; GAD-7; PHQ-9 and CORE-10			GAD-7: 9.6-8.1-8.2 PHQ-9: 12.3-11.2-10.5 Core-10- 18.2-17.2-16.6 (p = 0.013)
Kuyk et al., 2008 [56]	CBT-based inpatient therapy	Program lasting duration of inpatient stay (2-6 months)	No control	Weekly seizures observed and counted by nursing staff; BDI; STAI	Pre and post treatment and 6-month follow-up	Wilcoxon Matched Pairs and Pearson's correlations	Seizures: T!- 6.6 (9.8)- T2- 3.0 (4.7)- T3- 0.9 (1.8) (p = 0.002) BDI: 19.7 (9.4)- 11.5 (10.9)- 9.2 (7.5) (p = 0.001) STAI-trait: 47.2 (10.9)- 41.2 (10.9)- 36.7 (10.1) (p = 0.02) STAI- state: 46.1 (11.9)- 40 (11.8)- 33.3 (9.1) (p = 0.002)
Labudda et al., 2020 [57]	CBT-based inpatient therapy	Program lasting duration of inpatient stay (average 64.53 days)	No control	Seizures rated using self-made interview-based questionnaire; BDI, STAI	Pre and post treatment, 6-months follow-up	Seizure characteristics: ANOVA; Clinical & demographic characteristics: independent t-tests/ Mann-Whitney U	17 seizure free at posttreatment, 12 seizure free at follow-up BDI: significant main effect (F = 18.32, p < .001) significant decrease T1 to T2 (t = 6.02; p ,.001; significant difference t = 2.65 p < .01) significant increase t = -3.36 (p < .01) increase T2 to T3 STAI: Significant main effect (F = 3.11, p = .04) significant decrease T1 to T2 (t = 3.12, p < .01)
LaFrance et al., 2009 [62]	Individual CBT	12 1hr weekly sessions, delivered by experienced therapist	No control	Seizures self-rated using daily calendar plus collateral info from	Pre-treatment, 4, 8 and 12 months post enrolment	Paired t-tests & Wilcoxon signed	Seizures: T1- 17.2 (23.2) – T2-11.8 (19.7)-T3- 7.1 (14.6), t = 3.85, p = 0.001 MHRSD:14.6 (7.3)- 10.4 (7)- 11.6 (7.2), t = 2.056

				family; BDI, MHRSD, DTS			BDI: Significant decrease-19.1 (15)-18.5 (22.4)- 10.7 (7.8). t = 2.172, p = 0.01 DTS: significant decrease-58.9 (37.8)- 47(30)-36 (27.6) t= 2.886 p = 0.01
LaFrance et al., 2014 [63]	Individual CBT	12, 1hr, weekly sessions delivered by trained on-site therapist	1:1:1:1 treatment arms: CBT-(ip); flexible-dose sertraline, combined CBT-ip and sertraline, TAU	Weekly seizure calendars, BDI, BAI	Baseline, week 2, week 8 and posttreatment	Generalised linear mixed models	Seizures: CBT-ip condition: 51.4% fewer seizures (p = .01) significant CBT-ip w/ sertraline 59.3% fewer (p= .008) significant Sertraline and TAU: no significant change BAI: (*F*3,24 = 3.43; *P* = .03), BDI: (*F*3,30 = 4.38; *P* = .01) HDRS: (*F*3,24 = 3.25; *P* = .04),
LaFrance et al., 2020 [64]	Individual CBT	12 weekly sessions delivered online	No control	Self-reported weekly seizure calendar, BDI, BAI	Pre-treatment, midpoint, post-treatment	Generalised linear mixed models	Seizures: Significant reduction- 45.7% per month of treatment (.543, p = .0001) BDI: significant- 25.6-20.4 -15.0, p = .0024 Anxiety: significant- 25.5- 20.6- 16.7 p= .0034
Myers et al., 2017 [65]	Prolonged exposure therapy	12-15, 90 minute sessions	No control	Self-reported daily seizures, BDI	Pre and post-treatment	t-tests and Wilcoxon tests	Seizures: significant decrease- (Z= -3.413, p = 0.001) BDI: significant decrease- (27.00-8.5) to final session (13.44-7.94) t (15) = - 4.420, p < 0.0001

Streltzov et al., 2022 [66]	Group CBT and MBCT	Eight weekly sessions over the telephone delivered by a trained facilitator and co-facilitator with epilepsy	No control	Self-reported seizure frequency (weekly and monthly) PHQ-9; GAD-7	Baseline, session 8 and one-month follow-up	Descriptive statistics	Seizures- reduction of 3.75 (4.65) per month PHQ-9: Reduction of 3.33 (2.66) GAD: reduction of 1.83 (3.49)
Tilahun et al., 2021 [67]	Individual CBT	12 sessions delivered by psychologist	No control	Daily seizures in last 6 months, PHQ-9, GAD-7	Pretreatment, 3 months, 3 months postreatment	Two-sample t-tests for continuous variables and Fisher's exact tests for categorical	>3-month treatment: GAD-7: -2.9 (4.5) change, p = 0.008 PHQ-9: -3.4 (7.3) change, p = 0.008

Note: ACT = acceptance and commitment therapy; BAI = Beck Anxiety Inventory; BDI-II= Beck Depression Inventory-II; CBT= Cognitive Behavioural Therapy; CBT-ip = CBT-informed psychotherapy; CGI = Clinical Global Impression; CORE- 10 = Clinical Outcomes in Routine Evaluation-10; DASS-21 = Depression, Anxiety and Stress Scale-21; DBT = dialectical behavioural therapy; DTS = Distress Tolerance Scale; EEG = electroencephalogram; ET7 = Revised Emotional Thermometer Scale; GAD = general anxiety disorder; HADS = Hospital Anxiety and Depression Scale; HADRS = Hamilton Anxiety and Depression Rating Scale; LD = learning disability; MBT = mindfulness based therapy; MDD = major depressive disorder; MHRSD = Modified Hamilton Rating Scale for Depression; NOS = not otherwise specified; OCPD = obsessive compulsive personality disorder; OT = occupational therapist; PaD = panic anxiety disorder; PHQ-9 = Patient Health Questionnaire-9; PNES = psychogenic nonepileptic seizures; PTSD= posttraumatic stress disorder; RCT = randomised controlled trial; SMC= standardised medical care; STAI = State Trait Anxiety Inventory; TAU= treatment as usual TBI = traumatic brain injury

3.2. Mindfulness-based Therapy (MBT)

Two studies used an MBT approach [58] [59]. In the initial study [58] only 50% of six participants completed the mental health measures at all time points (6th and 12th session), so no statistical analyses were conducted for these measures, presenting scores only for information purposes. Most participants' weekly seizure frequency had markedly declined by the 6th session, (mean of 18 seizures reduced to 2.25), and were maintained by the 12th session (mean 2.67). Notable changes were identified in depression scores of participants that had completed measures at all time points, but only one participant showed improvement in anxiety score by session 12. The later study [59] had an increased sample size (N=26), yet treatment completion rate was low at 55%, and less than 60% of the selected sample did not participate, meaning the study was underpowered. Post-intervention, 50% of participants reported no seizures, and 70% had a 50% reduction in seizure frequency, decreasing by 0.12 episodes a week ($p = .002$). Anxiety and depression scores decreased slightly and did not reach statistical significance, although scores at baseline were within minimal ranges, providing small scope for benefit. The findings of the reviewed MBT studies demonstrate the effectiveness of MBT in reducing seizure frequency but not in alleviating psychological distress. The MBT protocol utilised in these studies is the first adapted for FS patients, and results indicate the potential benefits of applying mindfulness principles to emotion management on symptoms. However, neither of these studies used controls and both had small, underpowered, opportunistic samples. As such, due to these limitations, it is not possible to conclude that MBT is effective in alleviating psychological distress in FS. In addition, neither study evaluated longer-term benefits so the sustainability in seizure frequency reduction could not be confirmed.

3.3. Acceptance and Commitment Therapy (ACT)

Barret-Naylor et al.'s [67] case series examined the effectiveness and acceptability of a guided, self-help ACT intervention for individuals with FS. As the aim of ACT is not to directly target primary symptomology, seizure reduction was the secondary outcome, and psychological health, including psychological flexibility and quality of life, was the primary. Outcome measures were administered at baseline, postintervention, and at follow-up of one-week and one-month. Seven self-selected participants completed the study, so accuracy of diagnosis was not provided. The intervention comprised of chapters and exercises from an ACT self-help book. The participants that did not have existing mental health difficulties scored within the nonclinical range on the DASS-21 at baseline, so improvement could not have been determined, but the remaining four participants demonstrated reliable and clinically significant change postintervention. This improvement was clinically significant for two participants at one-month follow-up. Seizure frequency reduced considerably for all participants throughout the study, with three participants reporting no seizures at follow-up.

Overall, this study indicates the potential effectiveness of an ACT self-help intervention in alleviating the psychological impact of FS, and coincidentally improving seizure frequency. The study meets the recommended sample size for a case series. However, its sample selection was biased due to volunteer sampling methods and there was no control group. As this study measured psychological health, measured by the DASS-21, it is worth acknowledging its suitability in answering the current review question. The participants that demonstrated clinically reliable change initially indicated mental health difficulties and whilst it is not clear whether their reduced psychological health was related to their FS, these were the participants that maintained seizure reduction at follow-up. Currently, this is the only study to investigate an ACT intervention in individuals with FS and measure changes in psychological distress. As such, and considering the

potential selection bias of the study's sample, caution should be taken when generalising the findings to the FS population.

3.4. Cognitive Behavioural Therapy (CBT)

Goldstein and colleagues [50] conducted the first trial systematically measuring the effectiveness of CBT for FS. Seizure frequency was measured monthly and was assessed a month prior to treatment, posttreatment and at six-month follow-up, along with the mental health measures. Posttreatment, 13 participants experienced a 50% reduction in seizures and at follow-up, four were no longer experiencing seizure activity. Anxiety ($p < 0.05$) and depression ($p < 0.05$) scores also significantly reduced throughout treatment, were maintained at follow-up, and were supported by scores on the Fear Questionnaire, which demonstrated a significant decrease in avoidance of feared stimuli ($p < 0.05$). This study was a promising starting point for trials measuring CBT effectiveness, demonstrating high quality, supported by its low dropout rate, and valid and reliable data collection method. Nevertheless, this study had no control group, and did not report or control for participants already acquainted with psychological therapy, or prescribed psychiatric medications, considering three participants reported a coexisting psychiatric diagnosis at baseline.

A similar study was conducted by LaFrance et al. [62], measuring effectiveness of their CBT protocol, CBT-ip. Therapist adherence to the protocol was monitored by audiotape and randomised sessions were measured using a modified Cognitive Therapy Scale. Weekly seizure frequency was measured, and psychological health measures were completed at baseline, month one and posttreatment. 16 out of 21 participants reported a 50% seizure reduction and 11 of these reported no seizures. Mean scores on the BDI-II ($p = 0.01$) and DTS ($p = 0.01$) illustrated significant improvement in mood and anxiety. This study demonstrated strong quality, sharing

ratings with the Goldstein et al.'s [50] study across all constructs, however, for this study, it is worth considering the high number (62%) of participants who were already acquainted with psychotherapy, including CBT for four participants, and the increased number of participants taking psychotropic medication (76%), which may have potentially influenced depression and anxiety outcomes. Follow-up was not reported, so sustainability of benefits was not demonstrated. The session content of both CBT studies appeared to be similar and although comparison is difficult due to variation in measures, treatment outcomes did not noticeably differ. In addition, neither used controls and both had relatively small sample sizes recruited from single clinics in Western countries, limiting the generalisability of findings.

LaFrance and colleagues [64] extended their study to measure the effectiveness of CBT-ip when administered via telehealth. Results indicated a significant reduction in seizure frequency ($p = .0001$), in addition to a significant decrease in depression ($p = .0024$) and anxiety ($p = .0034$), demonstrating the potential suitability for administering CBT-ip to individuals who have difficulties in accessing face-to-face therapy. Although the treatment was provided in a range of clinics across North America, the sample was limited to the military veteran population. As such, the sample mainly consisted of males, older adults, and those with many comorbidities. This limited generalisability is reinforced by the use of a single therapist, lack of controls and sampling bias.

Bajaj et al. [55] used a control group in their study, comparing the effectiveness of CBT (N= 30) to standard medical care (SMC) (N= 20) of anti-anxiety and anti-depressant medication. Participant characteristics were not reported, however comorbid epilepsy or major mental illness (e.g.- psychosis), history of psychological treatment or current suicidality were included in participant exclusion criteria. Seizure frequency, depression and anxiety were assessed at baseline, on a monthly basis, and at posttreatment, and there were no differences between groups on these measures at baseline. At posttreatment, seizure frequency, anxiety and depression scores

statistically significantly decreased in the CBT group, although p-values were not reported. These significant differences were not demonstrated in the SMC group. Significant between-group differences in seizure frequency were also observed, but this was not significant for anxiety and depression scores. Although this study provided some evidence for the effectiveness of CBT in comparison to psychiatric medication there were several methodological limitations. Content of the CBT intervention was not reported so it is unclear whether a protocol was followed, or whether the intervention was adapted for FS. This is reinforced by the underreporting of treatment fidelity. It is also not clear whether a trained professional administered the intervention. No participant characteristics were reported, meaning it is unclear whether groups were balanced or stratified prior to randomisation. The randomisation method was also not reported, so it is ambiguous as to whether there were any researcher biases regarding group allocation. Although only 10% of participants in the CBT group withdrew, only 40% in the SMC attended regular follow-ups. As such, although this study demonstrates some evidence toward reduced anxiety and depression following CBT, there was no evidence to suggest it as a more beneficial treatment to SMC of psychiatric medication.

Goldstein et al. [60] and LaFrance et al. [63] also conducted pilot randomised controlled trails (RCTs) into the effectiveness of CBT for FS compared to SMC. Goldstein et al. [60] measured seizure frequency and anxiety and depression scores at baseline, posttreatment and at 6-month follow-up. Results indicated that relative to SMC alone, participants in the CBT group experienced a greater reduction in their seizure frequency posttreatment, maintained at follow-up. There were no reported changes in anxiety and depression. LaFrance et al.'s [63] RCT compared the effectiveness of CBT-ip (n= 9) to a range of FS treatments, including flexible-dose sertraline (n = 9), combined CBT-ip and sertraline (n = 10) or treatment as usual (TAU) (n = 10). Self-report questionnaires were completed at baseline, second session, eighth session and posttreatment.

There were no demographic differences between groups, although groups were not stratified based on baseline scores. Analyses indicated a significant reduction in reported monthly seizures in the combined ($p = 0.008$) and CBT-ip ($p = 0.01$) groups, which was not observed in the other treatment groups. For those receiving CBT-ip, achieving seizure freedom was over six times greater. In the CBT-ip group, significant improvements were observed on the Hamilton Depression Scale ($p < 0.001$), BDI-II ($p < 0.01$) and BAI ($p <0.001$). These differences were not observed in the TAU and sertraline groups, demonstrating CBT-ip alone to be the preferable intervention when supporting mental health outcomes. LaFrance et al. [63] demonstrates evidence for CBT improving specific mental health outcomes of anxiety and depression, whereas Goldstein et al. [60] did not, although low baseline scores may reflect minimal changes. The analysis by Goldstein et al. [60] demonstrated that protocol violations did not impact seizure outcome, but it is unclear as to whether this impacted anxiety and depression outcomes. Despite the studies' control, it is again worth considering their lack of generalisability. Although LaFrance et al.'s [63] RCT was multicentre, this still only consisted of three US clinics. Both studies also had low sample sizes. In addition, Goldstein et al. [60] did not report participant demographics of previous psychological support or current prescribed psychiatric medication, which may have influenced results. In comparison, between-group differences in baseline anxiety and depression scores in LaFrance et al.'s [63] study decreases the result's validity, demonstrating the differences in findings between these RCTs.

Tilahun et al. [67] aimed to replicate the CBT-ip protocol to examine the outcomes in their outpatient service. They used an observational, retrospective design, utilising patient clinic data. They also aimed to explore outcomes in patients who completed fewer sessions, and those that took longer than three months to complete at least seven sessions. Outcomes were completed at pre-treatment and three months posttreatment. No significant changes on any measure were

demonstrated at three months, however, individuals that attended sessions for longer than three months indicated significant improvement in anxiety and depression scores ($p = 0.01$). This infers that treatment is of more benefit to individuals with FS when treatment is longer, irrespective of the number of sessions provided. However, generalisability is difficult due to low sample size, lack of control group and following a reduced amount of people who had data available, indicating possibility of sampling bias.

The CODES trial [61] is the largest RCT to date measuring treatment effects in FS, recruiting from 27 clinics in Great Britain. Outcomes were assessed at baseline, six-months and 12-months after randomisation. No significant differences in monthly seizure frequency were identified between groups and a similar finding was observed on anxiety and depression scales, although significant differences were observed in general psychological functioning as measured by the CORE-10 ($p = 0.013$). However, the use of psychiatric medication prior to, or during participation, was not reported in this study which may have confounded the findings.

In summary, the findings for CBT's effectiveness for improving mental health outcomes for those with functional seizures collectively differs across studies of varying levels of control. However, the multi-centre RCT [61], which is of the strongest quality owing to its level of control, demonstrated CBT to be no more effective than SMC in improving anxiety and depression, although it did demonstrate significant effectiveness for overall psychological distress. However, it is again worth recognising the generalisability of this study which could be limited, considering its UK-based population. CBT-ip [63] did demonstrate significant results, and it was also demonstrated to be effective when delivered remotely [63].

3.4.1. Group CBT

Conwill et al. [68] and Cope et al. [69] both conducted pilot cohort-designed studies evaluating CBT-based group therapy for FS. Neither study demonstrated significant improvement on anxiety and depression scores, but did indicate significant improvement for emotional wellbeing, measured by the ET-7 ($p = 0.028$) [69] and the emotional wellbeing scale of the SF-36 ($p = 0.4$) [68]. In Conwill et al.'s [68] study, at baseline, four out of ten participants with FS experienced psychological difficulties of anxiety or depression however no significant associations between baseline mental health scores and demographic variables were identified. Withdrawals were not reported. In Cope et al.'s [69] study, mental health demographics were not reported, although 68% were prescribed anti-depressant medication, and 20% were prescribed anti-anxiety drugs, potentially confounding results and only 64% of the sample attended all sessions. Neither Conwill et al. [68] or Cope et al. [69] report the percentages of eligible participants who agreed to participate, and both studies acknowledge small sample sizes, limiting their generalisability and further decreasing validity. Intervention content and length did not appear too dissimilar between studies. As such, and perhaps explained by potential sampling bias and potentially ungeneralisable samples, neither study confirms effectiveness of group CBT for psychological distress in FS.

Streltzov et al. [66] recently conducted a pilot study assessing the feasibility of Project UPLIFT, a CBT-and MBCT-based self-help group management program. Six participants completed the treatment and only 25% of eligible participants agreed to participate, indicating a potential sample bias. Outcomes were assessed at baseline, posttreatment and at one-month follow-up, however analysis only comprised of descriptive statistics. At follow-up, average depression scores had decreased by 3.33 ($SD = 2.66$), and average anxiety scores decreased by 1.83 ($SD = 3.49$), suggesting a larger improvement for depressive symptoms, despite both scores suggesting moderate severity at baseline. Qualitative findings also suggested participants felt more able to manage their seizures and daily life at follow-up, illustrating the potential effectiveness of

combined cognitive-behavioural and mindfulness strategies for seizure conditions. While this study provided initial evidence for the acceptability of Project UPLIFT, its potential selection bias and lack of control, further reinforced by a small, homogenous sample are significant limitations.

Overall, the current studies assessing effectiveness of group CBT have produced little evidence into their benefits in improving mental health outcomes for individuals with FS.

3.4.2. CBT-based inpatient therapy

Two studies conducted individualised, inpatient CBT-based therapy [56] [57]. In Kuyk et al.'s [56] study, outcomes were measured at pre-treatment, discharge, and six-month follow-up. Patients were admitted to a separate unit of an epilepsy centre, specifically for treatment of their FS. Treatment lasted for an average of five months; it was unreported at what stage patients were discharged. Analysis demonstrated seizure frequency decreased significantly throughout the study with 50% of participants reporting seizure freedom. Between baseline and follow-up, trait ($p = 0.02$), and state ($p = 0.002$) anxiety and depression ($p = 0.001$) scores demonstrated significant improvement. There was no control group, no control over treatment duration and out of 26 participants, three withdrew. There were also no reported demographics in relation to participant familiarity with psychotherapy and prescribed medication, and sample size was minimal. There was also lack of control over treatment duration.

Labudda et al. [57] provided psychotherapy in their inpatient psychotherapy ward in Germany. Their weekly individual intervention consisted of combined dialectic-behavioural-therapy (DBT) principles and CBT. Outcomes were assessed at pre-treatment, discharge and 6-month follow-up. At discharge, 23% of patients reported seizure freedom, however this did not predict longer-term outcomes. There was a significant decrease in depression ($p = .01$) and anxiety scores ($p < .01$) at discharge however at follow-up, depression scores increased ($p < .01$) and there

were no significant changes in anxiety ($p = .58$). A comparative analysis was conducted, comparing clinical and demographic differences between participants who were and not able to achieve seizure freedom, finding those who became seizure-free had fewer mental health difficulties at baseline. In addition, although patients with comorbid epilepsy were able to discern their seizures, this was not controlled. The study did not have a control group, withdrawal rates were significant, and there was no reporting of consenting participants, risking sampling bias which was already increased due to the opportunity sample.

In summary, these studies demonstrated some evidence toward CBT-based, inpatient therapy improving psychological health in individuals with FS. The studies' findings differed regarding longer-term changes; however, these may have been impacted by Labudda et al.'s [57] participants having a high number of comorbid mental health difficulties at baseline. Both studies were conducted in European inpatient units, which although provides heterogeneity to a review consisting of UK and US studies, the findings of the effectiveness of CBT-based inpatient intervention cannot be generalised to an FS population accessing outpatient care, which is increased by their low sample size and bias and lack of control group.

3.4.3. Prolonged Exposure Therapy (PE)

PE is a manualised, CBT-based approach that targets the psychological effects of posttraumatic stress disorder (PTSD) [70]. Myers et al.'s [65] case series, aimed to demonstrate the effectiveness of PE for individuals with comorbid diagnoses of PTSD and FS. Thirteen out of 16 participants reported seizure freedom by the final session, and the three remaining participants had significantly lower seizure frequency ($p = 0.001$), maintained at follow-up. Mean depression scores showed significant improvement from baseline to final session ($p < 0.0001$) as did mean PTSD scores ($p < 0.0001$). However, the study's underreporting of sampling method potentially reduces

its quality, as does its lack of control. In addition, psychological measures were not taken at follow-up, so it is unclear whether the reduced depression scores were maintained. It is also worth considering the application of these findings, as PE is designed to only alleviate PTSD symptoms, and considering the research demonstrated earlier in this review, not all FS patients have experienced previous trauma. Although this study utilises psychological measures, it is unclear whether higher baseline depression scores are relative to the effect of FS, or PTSD.

4. Discussion

The aim of this review was to evaluate the effectiveness of CBT and third-wave interventions for alleviating the psychological distress associated with functional seizures. A series of interventions were reviewed including individual, group and inpatient CBT, ACT, MBT and PE.

Overall, the papers reviewed in this study provided mixed findings for the evidence of the effectiveness of CBT and third-wave approaches in improving psychological outcomes. Most papers included in this review utilised a CBT approach, which were also the only studies to use controls. The majority of papers in the review measured mental health outcomes using specific measures, however when considering the high comorbidities of FS with trauma [11] the risk of suicide [18] [15], the impact on individuals' coping [71] [72] and social interactions [19] [22] a more generalised psychological measure, such as the CORE-10 [73] is more appropriate in measuring psychological outcomes rather than focusing on anxiety and depression alone, supporting the findings of Goldstein et al. [61].

The studies measuring group CBT [68] [69] demonstrated significantly increased emotional wellbeing and Project UPLIFT improved depression scores yet not anxiety. Although, this study was conducted in the context of the COVID-19 pandemic, a period of increased stress and anxiety for all [74] [75], potentially a contributory, external factor to the minimal changes. In addition, the

protocol was initially developed for individuals with epilepsy, adapting only terminology and epilepsy-specific resource, with no additional psychoeducation added. Anxiety has increased prevalence in FS compared to epilepsy [11], suggesting the potential benefits of adding material specific to psychosocial management of FS. Further, controlled studies are necessary to explore the potential effectiveness of Project UPLIFT and other group CBT protocols for the FS population.

It is also necessary to acknowledge the differences in what controlled studies considered as SMC/TAU. LaFrance et al.'s [63] study was beneficial as it compared CBT to medical interventions, in addition to TAU, consisting of biweekly neurology follow-ups, demonstrating a psychological intervention to be more effective than antidepressant medication even when combined. This is supported by Bajaj et al.'s [55] trial, who provided psychiatric medication as SMC and observed no significant differences between groups. Content details of LaFrance et al.'s [63] TAU was unreported, unlike Goldstein et al., [60], whose SMC consisted of ongoing clinic psychoeducation with neuropsychiatry. Goldstein et al. [61] were not able to control SMC due to the study's multicentre design but provided guidelines of neurology and psychiatry follow-ups. However, the ecological validity of these treatment arms should be considered, as it is unfortunately not common for patients in the UK to receive further follow-ups following their diagnosis, instead often being referred to websites for further information about their condition [25]. In the US however, follow-up is often offered to patients but is not usually taken up [25] [76].

The studies assessing CBT-based inpatient therapy [56] [57] demonstrated significant improvement in mental health outcomes posttreatment, however Labudda et al. [57] did not observe these at follow-up. The multidisciplinary aspect of these treatments is representative of the current perception of effective treatment for FS and other functional symptoms. Due to the

variability of seizure aetiologies and functions, it is recommended patients are provided multidisciplinary individual treatment plans [77] [78], adapted to their clinical presentation, to target the arbitrary mechanism [4]. Within psychology, individualised treatments, considering CBT and third-wave models, in addition to systemic, psychodynamic and EMDR work, dependent on the cause of distress, is considered to be the more beneficial approach [76]. To the authors knowledge, one pilot study [79] has found this approach, based on the biopsychosocial model, to be effective in improving seizure outcomes. Inpatient treatment for FND has been found to provide greater certainty of co-ordinated, multidisciplinary therapy in a controlled environment [80] [81]. However, reviewing inpatient treatment in contrast to other, community-based interventions is difficult, as exposure to potentially triggering social and environmental conditions is limited [80] [81]. This may be a potential reinforcer of patients' psychological difficulties, potentially illustrating Labudda et al.'s [57] findings of increased depression scores at follow-up once patients had returned to their usual social environment. Although, this may have also been influenced by a higher number of participants having comorbid mental health difficulties at baseline, as Kuyk et al.'s [56] inpatients' improved mental health was maintained at follow-up. It would be beneficial to measure the effectiveness of these protocols in an outpatient setting, using a controlled study design. The positive findings of the CODES trial [61] provides further rationale for this, as although a more stringent CBT model was followed, intervention was formulation-based, providing flexibility to focus on individual seizure triggers.

The remaining studies measuring further third-wave approaches were not controlled, impacting the reliability of results. The evidence demonstrated for MBT was not substantial enough for it to be advised as an effective treatment for psychological outcomes, as changes of psychological distress were not found to be significant and studies were not controlled [58] [59].The

effectiveness of MBT in improving psychological outcomes has been demonstrated in the general population [82], so better controlled studies should be conducted prior to suggesting it as an effective intervention for alleviating psychological distress in PwFS. All studies included in this review took place in westernised countries, however under-represented individuals continue to face barriers in accessing therapy [83], as demonstrated by the demographic differences Baslet et al. [59] identified, such as ethnic background, age and education between completers and non-completers which is supported by pre-existing literature on characteristics of individuals who drop out of therapy [84]. As such, it is worth considering the potential attrition and sample bias impacting all of the review's studies' findings, indicating the need for such research to be expanded globally. Tilahun et al. [67] observed significant reductions in anxiety and depression when individuals were able to attend therapy more infrequently and for a longer period, which improves accessibility for individuals who find weekly, shorter therapy too intense, providing an intervention to also suit treatment needs. Although the literature has demonstrated no significant differences in outcomes in telehealth and face-to-face therapeutic interventions [85] [86] considering the physical and social restrictions of FS, telehealth may be a preferred and more comfortable method of engaging in therapy, aiding therapeutic outcomes in addition to the social connection that comes with group therapy. This finding is supported by Streltzov et al.'s [66] positive findings of their remote group intervention and the study by LaFrance et al. [64], who found improved anxiety and depression outcomes for their individual, online CBT trial. Nevertheless, as discussed, the validity and reliability of studies' findings are impacted by their lack of control and small samples, so it would be beneficial to explore the effectiveness of remote therapy for individuals with FS in a larger, controlled study. An additional way to improve therapy accessibility is self-help modalities, such as in the reviewed ACT intervention [67]. This study demonstrated positive findings. Nevertheless, this was an uncontrolled study and the only self-

help intervention included in this review. Whilst the participants were provided with weekly check-ins, the self-help mode of therapy omits the therapeutic benefit of a provider-service-user relationship [87] and the validating space to express distress. However, the benefits of this mode of providing ACT and mindfulness-base interventions across health populations including medically- unexplained symptoms [88] [89] and chronic pain [90] have been demonstrated, also supported by systematic review [91]. The ACT study [67] was the only in this review to measure psychological outcomes as a primary outcome, suggesting the benefits of not including seizure reduction as a primary therapy focus, aiding both improvements in mental health and seizure frequency. However, considering the study's methodological limitations, further controlled research would be beneficial.

PE [65] was found to significantly improve outcomes of depression, as well as trauma symptoms and seizure frequency. Trauma has demonstrated prevalence of 7-100% in FS, 15-40% higher than controls, suggesting trauma to be a risk factor of FS, and seizures to be a potential trauma response [11] [92] [93]. Nevertheless, many FS patients do not have a trauma history, and have felt frustrated and invalidated when the condition is assumed by professionals to be exclusively psychological [13] [14] [15] [16]. As such, and considering the study' s lack of control, caution should be taken in generalising these findings to the wider FS population, in addition to interpreting the results in relation to the review question. Significant reduction in depression scores was indicated, however it is unclear, without qualitative query, the aetiology of the elevated depression scores at baseline, which may be relative to the decrease in trauma symptoms rather than a reduction in the psychological impact of the condition.

When considering all reviewed interventions, it was apparent that statistically significant reductions in anxiety and depression scores were only observed when these were elevated at

baseline. Undoubtably, without qualitative query, the aetiology behind participants' mental health difficulties is unknown, as to whether they are related to their FS or other life factors. However, this provides some evidence for psychological interventions only being beneficial for when there is patient need. Nevertheless, all studies in the review also demonstrated some reduction in seizure frequency, indicating the benefit of psychological intervention for seizure outcome, supported by the previous meta-analysis [32]. Again, it is worth considering the ambiguous relationship between FS and psychological difficulties, known to be a risk-factor for, and consequence of, the condition. However, considering the noticed benefit of psychological interventions on both seizure and mental health outcomes when these are increased pre-treatment, it may be for these participants, psychological distress was associated with seizure triggers.

4.1. Limitations

A main limitation of this review is the varying quality of included studies. Many studies had no control group, making it difficult to attribute improvement in psychological distress to the effectiveness of the intervention alone. There was also lack of control of other extraneous variables, such as comorbid epilepsy, effects of already prescribed medication, including psychiatric and prior experience of psychological therapy across studies. The only controlled studies (n = 4) used a CBT model, and this included the largest RCT to date [61], providing favourable evidence for CBT, not based on model characteristics, but instead on validity and reliability of results. The evidence other approaches, specifically ACT, PE, and CBT-based inpatient therapy, is promising, but it is not yet appropriate to recommend these models for supporting the psychological impact of FS due to their lack of generalisability.

Many studies reported high withdrawal rates, which may be characteristic of accessibility of therapy for PwFS [94] [95], and some did not indicate the number of consenting participants. In

addition, the studies' volunteer or opportunistic sampling methods, where participants were referred by their clinician who may have also been the researcher, increases the likelihood of sampling bias. Furthermore, bias is increased in all studies by researchers' involvement in the therapeutic process, providing of outcome measures and/or awareness of control group allocation. This has increased difficulty when trialling psychological interventions, however increased risk of response bias and positive response expectancy impacts results [96]. In addition, the review's search only included abbreviations for several terms, increasing the possibility of valuable papers being missed.

This review focused on the effectiveness of psychological interventions in alleviating psychological distress in PwFS. Unfortunately, a majority of studies included measures of mental health and distress in their secondary analysis, instead focusing on seizure frequency. As such, interventions aimed to improve the cause of the condition, rather than its impact. Of course, this is a preferable approach, but for many individuals, the psychological processes of FS can also precipitate attacks, meaning it is perhaps just as important to focus on alleviating these processes [12] [22].

5. Conclusion, further recommendations, and implications

To summarise, the evidence of the effectiveness of CBT and third-wave interventions for improving the psychological impact of FS is varied, though promising. There are more established, and valid, findings for the effectiveness of individual CBT in improving overall psychological distress. Further, controlled, research should be undertaken for further third-wave approaches, in addition to group CBT and inpatient CBT-based therapy, before they can be established as a recommended approach. The review demonstrates that positive outcomes are more likely when there is increased distress at baseline, indicating that a psychological approach is more appropriate for individuals with comorbid mental health difficulties, which may be linked to

seizure triggers as well as the impact of living with the condition. Nevertheless, as seizure aetiology is unique to each patient, it is reductionist to recommend an approach, such as CBT, as effective for all patients. Further, controlled, research into formulation-based interventions, building on the previous pilot study measuring effectiveness of psychotherapy based on the biopsychosocial model [79] should be conducted. Nonetheless, this review provides a foundation for the evidence of CBT and third-wave approaches in alleviating psychological distress in PwFS.

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Part Two – Investigating The Role of Compassion in the Psychological Impact of Functional Seizures

This paper is written in the format ready for submission to the Journal of Neuropsychology. Please see Appendix C for the Guideline for Author Guidelines

Word Count: 4891

Abstract

Functional seizures (FS) present similar to epileptic seizures but are not characterised by disturbances in brain activity. Levels of self-blame and self-criticism are increased in this population, perhaps exacerbating the psychological impact of the condition, along with seizure severity. An increased ability to receive compassion from others and provide it to the self and others, known as the flow of compassion, can alleviate self-blame and self-criticism and as such, psychological distress. The present study aimed to investigate whether the flow of compassion moderates the relationship between functional seizure severity (SS) and psychological impact. 245 individuals with FS completed several questionnaires measuring their SS, levels of compassion, anxiety, depression and mental wellbeing and quality of life (QoL). A linear regression analysis was completed to analyse for moderation effects. Self-compassion was found to moderate the relationship between SS and mental wellbeing. No further moderating effects were established, although several predictive relationships were identified. The present study was the first to explore the flow of compassion in functional seizures, and provided initial evidence for the potential effectiveness of compassion-focused therapy, focusing on compassion to self, in this population. Larger, more controlled studies are recommended to investigate the further flows of compassion in this population.

Keywords

Functional seizures, compassion, mental health, mental wellbeing, quality of life

Introduction

Functional seizures (FS), also referred to as psychogenic, dissociative, or non-epileptic seizures [1] [2], present similar to epileptic seizures or other paroxysmal conditions but are not characterised by disturbances in brain activity [3] [4] [5]. Distinguishable symptoms of FS include lengthier duration of ictal episode [6] [7] [8], affective vocalisation including crying or yelling [8] [9] [10] [11], consciousness [8], increased head or body movement [8] [12] [13], pelvic thrusting [8] [12] [14] and asynchronous jerks [8] [12].The aetiopathogenesis of FS is complex and distinctive for each individual, with the current consensus moving from a complete psychogenic cause to one that is interdisciplinary and comprehensive, incorporating biopsychosocial, cognitive and neurological risk factors [3].

Despite this developing understanding, individuals with FS, and those with other functional neurological disorders (FND), continue to be misunderstood, stigmatised, and invalidated [15] [16], with the risk of stigma reported to be 42% higher in FS than in epilepsy [17]. Many individuals have described their interactions with medical professionals as negative, their seizures being assumed to be fabricated for secondary gain, or caused by psychological trauma or distress, with some professionals believing the condition does not exist. As such little compassion and empathy is provided toward the distressed patient, prompting feelings of hopelessness, shame and self-blame, leading to self-stigmatisation [18] [19] [20] [21] [22] [23]. Living with FS also has a significant impact, as many individuals are critical toward their condition, experiencing increased levels of self-blame and decreased self-compassion around the uncontrollable nature of the condition and feeling isolated as a result of social exclusion and loss of independence [17] [20] [23]. These experiences amplify the psychological impact of FS, increasing stress, anxiety, low

mood and for some individuals, suicidal ideation [17] [22] [24], which may also impede symptom management [19] [25].

Besides recommending further neurological assessment if functional seizures are suspected [26], there remains no recommended care pathway for individuals once diagnosed in the UK. There is currently more robust evidence for psychological treatment for FS, although it has not yet been established which psychological model is most beneficial [27]. However, it has been proposed that seizure outcomes should not be the sole focus of treatment [28] as alleviating psychological factors may be more important, identified as stronger determinants of quality of life (QoL) [29] [30].

Emotional processes of self-criticism, shame, and self-blame appear to be prevalent in individuals with FS [17] [21] [22]. Compassion-focused therapy (CFT) adopts a non-blaming stance toward these distressing human processes, understanding them as the product of a dominating threat affect regulation system, impeding access to a more safe, content and soothed system [31]. As such, CFT aims to alleviate distress by increasing an individual's capacity to receive compassion and provide it to themselves and others, understood as the flow of compassion [32]. Therefore, it is suggested, by building compassion, people with FS (PwFS) can grow to develop an understanding of the condition and learn to manage it by instilling hope, calming the mind and decreasing vulnerability to psychological difficulties [31 [32].

The concept of compassion has been explored within a range of physical health diagnoses including irritable bowel syndrome, arthritis, and diabetes, with increased self-compassion identified as related to engagement in illness-related self-care and coping [33] [34]. Short-term,

virtual, CFT has been demonstrated effective in improving the mental health of individuals with chronic illness [35] and similar findings have been identified for group CFT for multiple sclerosis patients [36]. Self-compassion has been demonstrated to alleviate the psychological impact of experiencing epileptic seizures [37] and has also been identified as related to anxiety, depression, and coping efficacy in individuals with FS [38]. To date, the three flows of compassion: self-to-self, self-to-others and others-to-self, have not yet been explored in PwFS and would provide a more comprehensive view of the functions of compassion in the psychological impact of FS. The evidence suggests PwFS may have difficulties in receiving compassion, by self-isolating out of fear of burdening others and feeling as though they need to protect their families from their condition [20] [23] [25]. Alleviating this difficulty may allow individuals to adopt pro-social coping mechanisms in turn reducing anxiety around experiencing an episode. Increasing self-compassion may lead individuals to be less self-critical and self-blaming around their seizures [17] [21] [22] and increased compassion for others would perhaps protect from the intense emotions when experiencing dismissive interactions with others, such as medical professionals [17] [18] [21] [22] [23], preventing internalisation of perceived criticism.

There is growing evidence to suggest there is relationship between seizure severity (SS) and psychological distress. The relationship between SS and QoL has been identified in people with epilepsy [39] [40], independent of seizure frequency [41]. In PwFS, emotion regulation difficulties have been associated with SS [42] and it has been suggested experiences of distress contribute to the maintenance of the condition [19] [24]. However, to the author's knowledge, there is no available research investigating a relationship between SS and mental health and wellbeing.
It has been suggested interventions for FS should focus on lessening the condition's psychological impact. Processes such as self-criticism, shame and self-blame have been identified as prevalent in

FS and alleviating these may also lessen the psychological impact of the condition. Consequently, exploring FS from a compassionate perspective may be a novel approach in providing insight into the relationship between functional seizures and their psychological impact, potentially providing evidence into offering compassionate interventions such as CFT to individuals with FS. As such, the present study aimed to measure the three flows of compassion in individuals with FS, investigating their moderating effect on the relationship between functional SS and their psychological impact. Psychological impact was encapsulated through QoL, mental wellbeing and mental health factors of anxiety, depression, and stress, and compassion was measured through the three flows of compassion, self-to-self; self-to-others and others-to-self. Therefore, the current study investigated the following research question:

Do the three flows of compassion significantly moderate the relationship between SS and psychological distress?

Method

Design

A quantitative, cross-sectional design was adopted. Data were collected through a self-report online survey. Ethical approval was gained from the Faculty of Health Sciences Research and Ethics Committee at the University of Hull in June 2022 (Appendix F).

Participants

A power calculation using G Power Version 3.1.9.7 [43] indicated that a sample size of 223 would achieve 80% power to detect a small effect size of .05. Unfortunately, there was no available research that could have been used to predict a likely effect size for the research question. As analysis of the current research question would involve testing of three interactions, this was considered to likely have a small effect size. Recruitment took place between August 2022 and

March 2023. A total of 245 participants were recruited via paid social media advertisement to increase reach, and with the support of FND charitable organisations FND Hope, FND Dimensions and FND Action. Participants over the age of 18, who had received a formal diagnosis of functional seizures, were proficient in the English language and had capacity to provide informed consent and complete self-report measures were included in the study. Due to potential difficulties in distinguishing between seizures [44], participants with a co-morbid epilepsy diagnosis were excluded; as were individuals prescribed anti-epileptic medication due to side effects being a potential predictor of QoL [29]. Participants self-screened using the inclusion and exclusion criteria, meaning they were unable to proceed with the study if they did not meet the criteria. Initially, individuals were only able to participate if they lived in the UK, however following recruitment difficulties, the survey was made available internationally.

Measures

Demographic information (Appendix M)

Participants provided their age and gender, and the number of years since receiving their diagnosis. When the study was made international, participants completed an additional question of their country of residence.

Seizure severity (SS) (Appendix N)

The Liverpool Seizure Severity Scale 2.0 (LSSS) [45] is a measure of individuals' SS. The scale includes 12 Likert-scale items based on the participants' most severe seizure of the past four weeks, totalling a single unit-weighted scale from 0-100, with higher scores indicating increased severity. Although originally developed for use as a measure in epilepsy [46], the scale has demonstrated good reliability ($\alpha > .80$) and validity ($\alpha > .70$) in PwFS [38].

Flows of compassion

The compassion to self and compassion for others subscales of the Compassion Engagement and Action Scales (CEAS; see Appendix O) [47] were used in the study. Both scales include 13 Likert-scale items demonstrating high internal validity (α = .72 - .94) [46]. Higher scores represent greater self-compassion and greater compassion for others. The Engagement Scale measures an individual's sensitivity to suffering and motivation to address it and The Action Scale measures their ability to engage in action in an attempt to reduce distress [47]. The compassion from others subscale of the Fears of Compassion Scale (FOCS; see Appendix P) [48] was used to measure compassion from others due to its increased construct validity in measuring an individual's openness to receiving compassion from others in comparison to the CEAS. This is because the CEAS is thought to measure an individual's perception of other's compassion toward themselves rather than their receptiveness and openness to allowing compassion in [47]. The FOCS compassion from others subscale consists of 13 Likert scale items, demonstrating high internal validity (α = .85) [48]. Higher scores on this scale indicate a greater reluctance to accept compassion from others.

Mental health

The depression, anxiety, and stress scale (DASS-21; see Appendix Q) [49] consists of three subscales, each consisting of seven Likert-scale items all demonstrating good reliability (α = .88, .82 and .90 respectively) and replicated convergent and discriminant validity from the full version [50] [51]. This scale was selected due to it including a subscale measuring stress. Considering its prevalence in PwFS [17] [24], measuring this in the current sample was considered beneficial. Cut-off scores are demonstrated in the results section of this paper, with higher scores representing increased mental health difficulties.

Mental wellbeing

The Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMEBS; see Appendix R) [52] consists of seven Likert scale items providing a single summary score indicating participants' overall mental wellbeing from the past two weeks. Scores range from 7-35, with higher scores indicating greater mental wellbeing. For the purpose of this study, mental wellbeing is defined as positive psychological functioning, which can be experienced simultaneously with mental distress. As such, it was considered important to measure positive mental wellbeing and mental distress as two separate constructs [53]. The shorter-version of this scale was selected as it provides more focus on psychological functioning, has demonstrated good reliability (α = .84) [54] and reduces order effects of fatigue.

Quality of life

Health-related QoL is reduced in PwFS [55] and has previously been predicted by psychological factors [29] [30] so it was therefore thought to be important to include as measure of psychological distress in the current study. The Patient-Weighted Quality of Life in Epilepsy inventory (QOLIE-10-P; see Appendix S) [56] was selected. Although the survey was originally developed for an epilepsy population, it is currently the most used measure within functional seizure research [29]. The scale demonstrates good reliability for individual items (r = 0.48 – 81) and scales (r = 0.55- 0.77), with scores ranging from 11-62 and lower scores indicating better quality of life [56].

Procedure

Upon selecting the link to the study, participants were presented with the study's information sheet detailing the study's rationale and procedure and potential risks of taking part, such as the possibility of triggering a seizure. If the participant still wished to take part, they were then able to proceed to provide their informed consent. Once consent was provided, the participant proceeded

onto the screening questions, where they were able to confirm they fit the study's inclusion and exclusion criteria. If the participant met all criteria, they were then able to complete the survey of all measures detailed above. Upon completing the survey, the participant was then presented with a debrief sheet, detailing contact details of relevant sources of support. As the current study took place online and remained anonymous, direct support, or assessment of capacity for participation, was not able to be completed. This was managed by the above procedure. Overall, participation was estimated to take between 35-45 minutes.

Data analysis

All statistical analyses were conducted using SPSS for Windows Version 27 [57]. The data was screened for outliers using box plot analysis. Outliers were identified in the QoL outcome variable and in predictor variable compassion from others. To keep outliers in the data set, bootstrapping (1000 samples) was applied to the analysis. The data met the assumption of independent errors with all Durbin-Watson values being close to two. Skew and kurtosis outputs were observed and demonstrated all data sets to be normally distributed, apart from years since diagnosis. To adjust this skew, log and square root transformations were applied to this variable and as the log transformation was found to be closer to zero, this was utilised in the analysis. Variance inflation factors (VIFs) and tolerance statistics were observed to identify multicollinearity in the data set. No VIFs exceeded 10, and no tolerance statistics were below 0.2 indicating no concern. Scatterplots were utilised to observe for heteroscedasticity across all outcome variables, all of which were well distributed, meeting the assumption of homoscedasticity (see Appendix T). Bivariate correlations were conducted to establish relationships between variables. To measure the study's research question, a multiple regression model was used. Demographic variables of age, gender and years since diagnosis were entered into the first block, followed by flow of

compassion variables and seizure severity in the second block. Two-way interactions between severity and each flow of compassion variable were entered into the third block. Moderation effects were identified should statistical significance (p = < 0.05) be determined for interaction variables.

Results

Sample characteristics

Sample characteristics are outlined in Table 1. 245 individuals diagnosed with FS participated in the study. Participants' average length of time since receiving a diagnosis was 4.4 (SD 5.7) years. In the previous 4 weeks, 214 (87.3%) participants had experienced a seizure, an average of 10 (IQR = 27) seizures were experienced in total. Due to the skew in this data set, the median is reported.

Table 1.

Sample characteristics

Age	n(%)	Gender	n (%)	Country of residence	n (%)
18-25	69 (28.2)	Female	214 (87.3)	UK	183 (74.7)
26-39	87 (35.5)	Male	18 (7.3)	USA	27 (11)
40-60	76 (31)	Non-binary	8 (3.3)	Australia	11 (4.5)
60+	13 (5.3)	Other/prefer not to disclose	5 (2)	Canada	9 (3.7)
				Netherlands	4 (1.6)
				Ireland	3 (1.2)
				Germany	2 (0.8)
				New Zealand	2 (0.8)
				Spain	2 (0.8)
				Costa Rica	1 (0.4)
				Belgium	1 (0.4)

Seizure severity

Table 2 demonstrates the sample's average responses on provided questionnaires. Participants' SS was similar to samples in recent studies (M=52.5, SD= 21.8 [19]; M=60, SD =22.5 [38]).

Flows of compassion

Participants' compassion for others on both action and engagement scales were higher in relation to sample norms of M=29.97 (SD=6.79) and M=41.59 (SD=9.73) respectively [47]. However, participants demonstrated higher engagement (M= 23.67, SD=6.41) but lower action (M=26.15, SD= 7.40) for compassion to self, suggesting participants had an increased ability to pay attention to distress, but a reduced ability to compassionately address this in comparison to other research samples [47]. The present sample was less likely to accept compassion from others than the

general population (M = 15.28, CI (95%) = 11.66, 18.90) and shares similar difficulties with the average clinical population (M= 25.62, CI (95%) = 18.24, 33.01) [58].

Mental health

Based on the cut-off scores for the DASS-21 [50] (Table 3), the current sample demonstrated a mean stress score in the moderate range, an average anxiety score in the extremely severe range, and an average depression score in the severe range.

Mental wellbeing

Comparing to UK norms (M=23.5 (SD = 3.9); [54]), participants' mental wellbeing is considered to be below average.

Quality of life

To the author's knowledge, there are no cut-off scores or norms established for the QOLIE-10-P. A study utilising the measure in both an epileptic and functional seizure population has been observed to allow for comparison. The current sample's score demonstrates greater QoL in contrast to an epilepsy group (M = 40.34) but worse QoL in contrast with the functional seizure group (M = 32.77). Standard deviations were not reported in this study [59].

Internal Consistency

Reliability of individual measures were tested using Cronbach's Alpha. Values are demonstrated in Table 2. Most measures indicated good reliability, with values above 0.7 [60], with the exception of the individual engagement and action scales for compassion to self and compassion for others. This is considered in the study's limitations.

Table 2.

Descriptive statistics and internal consistencies of each measure

Measure	Mean	SD	Range	Cronbach Alpha (α)
Seizure severity	53.06	15.56	72.50	.77
Compassion to self (engagement)	34.78	9.65	54.00	.61
Compassion to self (action)	24.62	6.40	36.00	.60
Compassion to self (total)	57.85	16.48	87.00	.76
Compassion to others (engagement)	45.40	10.94	53.00	.68
Compassion to others (action)	32.31	6.90	36.00	.67
Compassion to others (total)	77.72	16.64	86.00	.79
Compassion from others	23.64	12.19	52.00	.91
Stress	22.69	10.78	42.00	.86
Anxiety	21.22	11.17	42.00	.83
Depression	20.92	12.74	42.00	.87
Mental wellbeing	19.24	5.25	24.00	.87
Quality of life	36.11	7.19	41.00	.73

Table 3.

Cut-off scores for the DASS-21

	Depression	Anxiety	Stress
Normal	0-9	0-7	0-14
Mild	10-13	8-9	15-18
Moderate	14-20	10-14	19-25
Severe	21-27	15-19	26-33
Extremely severe	28+	20+	34+

Correlational analyses

All three mental health variables (stress, anxiety and depression) were significantly negatively correlated with compassion to self and significantly positively correlated with compassion from others, suggesting those more able to provide themselves compassion and accept it from others also had reduced mental health difficulties. These variables were also significantly positively correlated with SS, meaning increases in SS was associated with increases in mental health problems. Similarly, mental wellbeing was found to be significantly positively correlated with self-compassion and negatively correlated with compassion from others, suggesting those with better mental wellbeing are also able to be compassionate toward the self and be more accepting of compassion from other people.

QoL was significantly negatively correlated with compassion to self and positively correlated with compassion from others, indicating those who struggled to provide self compassion and accept it from others also had poorer QoL. QoL was significantly positively correlated with compassion to others, suggesting those more able to attend to others' distress and provide compassion also had reduced QoL. QoL was also significantly positively correlated with seizure severity, meaning as SS increased, QoL decreased.

Table 4.

Correlations between all outcome and predictor variables

Variables	Compassion to self	Compassion to others	Compassion from others	Stress	Anxiety	Depression	Mental wellbeing	Seizure Severity	QoL
Compassion to self	-	.451**	-.287**	-.196**	-.233**	-.325**	.480**	.013	-.181**
Compassion to others		-	-.072	-.011	.022	-.006	.111	.063	.171*
Compassion from others			-	.582**	.550**	.567**	-.493**	.216**	.326**

Stress	-	.725**	.667**	-.537**	.210**	.440**
Anxiety		-	.667**	-.524**	.282**	.485**
Depression			-	-.704**	.196**	.539**
Mental wellbeing				-	-.133	-.491**
Seizure severity					-	.279**
QoL						-

Note: higher QOL scores indicate lower QOL and higher compassion from other scores indicate poorer ability to receive compassion.

**Significance at the 0.01 level (2-tailed)
*Significance at the 0.05 level (2-tailed)

Research question: Does the flow of compassion moderate the relationship between seizure severity and psychological distress in PwFS?

The current study aimed to measure whether the flows of compassion would have a moderating effect on the relationship between functional SS and psychological distress.

A significant interaction identified was between SS and mental wellbeing with self-compassion playing a role in the negative relationship between SS and mental wellbeing (Table 5). This finding corroborated with correlational analyses. Self-compassion also approached significance as a moderator between severity and QOL (p= 0.079). No further significant interaction variables were identified for the remaining outcome variables, indicating that compassion to and from others, did not moderate the relationship between SS and psychological impact and self-compassion did not moderate the relationship between SS and mental health within the current sample.

As demonstrated in Table 6, stress was found to be significantly positively predicted by compassion from others, as was anxiety ($p < 0.001$; see Table 7) and depression ($p < 0.001$, see

Table 8), meaning an increased ability to receive compassion from others led to decreased stress, anxiety and depression. Depression was also significantly negatively predicted by compassion to self, meaning an increased ability to provide self-compassion indicated reduced depression. Mental wellbeing was significantly positively predicted by self-compassion, meaning increased self-compassion led to increased wellbeing, and negatively predicted by compassion from others ($p < 0.001$; see Table 8), meaning mental wellbeing worsened when participants struggled to accept compassion from others.

QoL was the only outcome variable found to be predicted by all compassion variables at $p < 0.001$ (see Table 9). A negative direction was observed between self-compassion and QoL, meaning an increased ability to provide compassion to the self indicated increased QoL. Positive relationships were identified between QoL and the remaining compassion variables, indicating that an increased ability to provide compassion to others predicts poorer QoL, and being more open to receiving compassion from others predicts improved QoL. These findings are corroborated by the current study's correlational analyses. Reduced QoL was also predicted by reduced seizure severity ($p <0.001$).

Table 5.

Linear regression analysis examining the associations between age, gender, years since diagnosis, the flow of compassion and seizure severity on wellbeing

Variables	Beta	SE†	t	p-value	Lower 95% CI‡	Upper 95% CI
Block 1						
Age	.053	.466	.722	.471	-.582	1.256
Gender	-.127	.927	-1.807	.072	-3.502	.152
Time since diagnosis	.032	.374	.454	.650	-.568	.907
Block 2						
Compassion to self	.416	.020	6.530	<.001	.093	.173
Compassion to others	-.089	.019	-.1443	.150	-.064	.010
Compassion from others	-.376	.025	-6.267	<.001	11.941	34.519
Seizure Severity	.073	.019	-1.268	.206	-.061	.013
Block 3						
Seizure severity x compassion to self	.788	.001	2.453	.015	.001	.006
Seizure severity x compassion to others	-.515	.001	-1.356	.177	-.004	.001
Seizure severity x compassion from others	-.006	.002	-.023	.981	-.003	.003

† SE = Standard Error,

‡ CI = Confidence Intervals

Table 6.

Linear regression analysis examining the associations between age, gender, years since diagnosis, the flow of compassion and seizure severity on stress

Variables	*Beta*	*SE*	*t*	*p-value*	Lower 95% CI	Upper 95% CI
Block 1						
Age	-.209	.958	-2.936	.004	-4.701	-.924
Gender	.117	1.905	1.697	.091	-.523	6.987
Time since diagnosis	-.017	.769	-.246	.806	-1.705	1.326
Block 2						
Compassion to self	-.058	.044	-.890	.374	-.125	-.047
Compassion to others	.040	.040	.630	.529	--.054	.105
Compassion from others	.527	.055	8.589	<.001	.362	.577
Seizure Severity	.086	.041	1.453	.148	-.021	.139
Block 3						
Seizure severity x compassion to self	-.502	.003	-1.520	.130	.010	.001
Seizure severity x compassion to others	.335	.003	.858	.392	-.003	.008
Seizure severity x compassion from others	.246	.003	.939	.349	-.004	.010

† SE = Standard Error,

‡ CI = Confidence Intervals

Table 7.

Linear regression analysis examining the associations between age, gender, years since diagnosis, the flow of compassion and seizure severity on anxiety

Variables	*Beta*	*SE*†	*t*	*p-value*	Lower 95% CI‡	Upper 95% CI
Block 1						
Age	-.232	.978	-3.223	.001	-5.079	-1.224
Gender	.047	1.945	.684	.495	-2.503	5.164
Time since diagnosis	.047	.785	.676	.500	-1.016	2.078
Block 2						
Compassion to self	-.150	.045	-2.284	.023	-.190	-.014
Compassion to others	.113	.041	1.779	.077	-.008	.155
Compassion from others	.464	.056	7.512	<.001	.309	.529
Seizure Severity	.165	.042	2.774	.006	0.33	.197
Block 3						
Seizure severity x compassion to self	-.332	.003	-.996	.321	-.009	.003
Seizure severity x compassion to others	.133	.003	-.338	.736	-.006	.004
Seizure severity x compassion from others	.179	.004	.678	.498	-.005	.009

† SE = Standard Error,

‡ CI = Confidence Intervals

Table 8: Linear regression analysis examining the associations between age, gender, years since diagnosis, the flow of compassion and seizure severity on depression

Variables	Beta	SE†	t	p-value	Lower 95% CI‡	Upper 95% CI
Block 1						
Age	-.134	1.118	-1.860	.064	-4.284	.125
Gender	.163	2.224	2.358	.0199	.859	9.627
Time since diagnosis	-.017	.897	-.241	.810	-1.985	1.553
Block 2						
Compassion to self	-.241	.050	-3.768	<.001	-.286	-.090
Compassion to others	.122	.046	1.972	.050	.000	.181
Compassion from others	.476	.062	7.900	<.001	.369	.614
Seizure Severity	.092	.046	1.585	.114	-.018	.165
Block 3						
Seizure severity x compassion to self	-.503	.003	-1.544	.124	-.011	.001
Seizure severity x compassion to others	.224	.003	.580	.562	-.004	.008
Seizure severity x compassion from others	-.205	.004	-.795	.428	-.011	.005

† SE = Standard Error,

‡ CI = Confidence Intervals

Table 9.

Linear regression analysis examining the associations between age, gender, years since diagnosis, the flow of compassion and seizure severity on QoL

Variables	Beta	SE†	t	p-value	Lower 95% CI‡	Upper 95% CI
Block 1						
Age	.046	.619	.634	.527	-.828	1.613
Gender	.115	1.231	1.644	.102	-.403	4.453
Time since diagnosis	-.136	.497	.-1.934	.054	-1.941	.019
Block 2						
Compassion to self	-.239	.030	-3.431	<.001	-.160	-.043
Compassion to others	.259	.027	3.844	<.001	-.160	-.043
Compassion from others	.256	.037	3.898	<.001	.071	.217
Seizure Severity	.266	.027	4.212	<.001	23.648	56.381
Block 3						
Seizure severity x compassion to self	.617	.002	1.763	.079	.000	.007
Seizure severity x compassion to others	.369	.002	.893	.373	-.002	.005
Seizure severity x compassion from others	.002	.002	.983	.327	-.002	.007

† SE = Standard Error,

‡ CI = Confidence Intervals

Discussion

The aim of the current study was to establish whether the flows of compassion moderated the relationship between seizure severity (SS) and their psychological impact. One very small significant moderation effect was found where self-compassion acted to dampen the negative relationship between SS and wellbeing. Significant correlations were identified between SS and stress, anxiety and depression. This is in line with previous studies identifying relationships between psychopathology and SS [42], and SS and emotional regulation difficulties [41]. The identified relationship in the current study, between SS and reduced QoL, contradicts previous research whereby no relationship was identified in a functional seizure population [61] [62] [63]. No correlation was identified between SS and wellbeing, although this may be explained by the moderating effect of self-compassion weakening this relationship. Therefore, in the current sample, it can be implied there is somewhat of a relationship between SS and psychological impact across a range of outcomes.

Improved QoL was also significantly correlated with increased compassion to self and accepting compassion from others. Previously in a functional seizure population, a relationship between self-compassion and QoL was not identified [38]. However, differences in the QoL measure may explain this difference, as this relationship has been previously identified in people with chronic illness [64]. It is understood this study is the first to explore the relationship between QoL and ability to receive compassion from others in a clinical population. However, given what is understood around the regulatory impact of receiving compassion on social isolation [48], the association between social isolation and reduced QoL [63] [64] [65] and the prevalence of isolation in a functional seizure population [17] [20] [23] [66], it makes sense that these correlations are

being identified in the current study. Reduced QoL was correlated with compassion for others, meaning as the ability to provide compassion to others increased, QoL decreased. Whilst this may seem unexpected, a possible explanation for this relationship is the potential self-sacrificing nature of providing others compassion. Altruism has been considered a significant personal resource to disperse [48], and so for a population with already depleted energy [67], compassionate engagement and action may instead have the unintended effect and as such, decrease QoL. This is supported by the current sample's improved ability to provide others compassion (M = 77.34, SD = 16.73) compared to provide self-compassion (M= 57.29, SD = 15.97).

Compassion to self was found to significantly, negatively predict depression, in line with previous research in an epilepsy population [37]. Self-compassion has been considered an alternative to self-criticism [47], a protective factor against the development of depression [68]. As self-criticism is prevalent in the FS population [17] [21] [22], it follows that an increased ability to pay attention to and alleviate one's own suffering can alleviate depression while managing the condition. Compassion to self was also found to significantly predict wellbeing, a finding previously identified in the general population [69]. In addition, the ability to accept compassion from others was significantly associated stress, anxiety, depression and wellbeing, in that these problems increase the less able an individual is to accept compassion from others. Gilbert et al. [47] discuss how for some, affection and kindness from other people can be threatening, particularly for self-critical and isolated individuals. As discussed, self-criticism is prevalent in the FS population, as is isolation following social exclusion out of fear of burdening others or being vulnerable in public [17] [20] [23] [66]. In addition, many individuals with FS report difficult experiences with other people, be it invalidating interactions with medical professionals [17] [18] [21] [22] [23], heightened sensitivity and distress from friends and family [20] [66] or general stigmatisation [17] [70]. Considering the

evidence demonstrating poor mental health following these experiences [17] [22] [24] and the potential for compassion from others to initiate a threat response [48], this finding is unsurprising. This is corroborated by the sample's decreased ability to receive compassion from others in comparison to the general public and findings from correlational analyses.

QoL was the only outcome variable found to be predicted by all compassion variables and the directions of these relationships are corroborated by the current study's correlational analyses. As previously mentioned, the literature exploring an association between QoL and the flow of compassion is limited, however this finding is in line with studies investigating self-compassion and QoL in other health conditions. Pinto-Gouveia et al. [64] found self-compassion to significantly predict depression, stress and QoL in cancer patients and Nery-Nurwit et al. [71] established self-compassion to directly influence health-related QoL in those with multiple sclerosis. In the general population, self-compassion has also been indicated as a greater predictor of QoL than mindfulness for individuals with anxiety and depression [72].

One interaction was identified as significant in the present study, between SS and compassion to self for mental wellbeing. This can be interpreted as self-compassion acting as a moderator on the negative relationship between SS and wellbeing. For example, an individual who experiences severe FS may be able to improve their mental wellbeing to some degree by adopting a self-compassionate approach in their lives. Wellbeing in the current study was measured using a measure focusing on positive mental wellbeing, which encapsulates happiness and life satisfaction as well as positive psychological functioning, of interpersonal relationships, self-development, autonomy and self-acceptance. A two continua model has been considered, meaning it is possible that positive mental wellbeing can be experienced in the presence of mental health difficulties

[53]. Mental wellbeing in the present sample was demonstrated to be below average, which is unsurprising considering the above definition and the evidence around difficulties those with FS face provided throughout this paper. In addition, for PwFS, relationship difficulties have been identified as significantly correlated with depression and anxiety [61] and previously identified avoidance and emotion-focused coping behaviours [73] [74] [75] would indicate reduced self-acceptance, self-development and autonomy. Wellbeing was found to be negatively correlated with SS, indicating those with increased mental wellbeing, had reduced SS; although this relationship was not significant, perhaps explained by the moderating effect of self-compassion. The ability to engage in compassion to self was found to be increased in the current sample, indicating that participants were motivated and able to pay attention to their own suffering, and although self-compassionate action was low, this flow of compassion was positively correlated with SS. Self-compassion can be considered a protector against mental health difficulties by reducing factors such as isolation and self-judgement; and it is also an enforcer of positive wellbeing [47] [76], which as suggested above, is separate from psychological difficulties [47] [77]. The present study's finding is in line with previous research exploring positive psychology constructs in therapy students, finding self-compassion to be the largest predictor of mental wellbeing [78], and in another study where self-compassion was found to be a larger predictor of wellbeing than mindfulness [79].

Limitations

Limitations of this study include the use of an online, self-report survey method. This reduces reliability and validity of results by increasing sampling and response biases, exacerbated by potential wrongful interpretation of questions, social desirability and introspective abilities. Although measures utilised were of considerable reliability and validity, some survey applicability

in a FS population could be limited, particularly the QOLIE-10-P and the LSSS-3 which were originally devised for individuals with epilepsy. The QOLIE-10-P includes questions regarding anti-epileptic medications (AEDs), which have been previously identified as a significant predictor of QoL (Jones et al., 2016). This was initially controlled for in the present study by including prescribed AEDs in the participation exclusion criteria. However, for copyright reasons, the QOLIE-10-P was not modified to exclude such questions. Despite a statement in the survey, several participants responded to the question. As inclusion and exclusion criteria could not be properly controlled due to the nature of the study, this poses the question of whether participants took part without adhering to participatory criteria or whether questions were simply misread. In addition, due to differences in healthcare status and access differentiating across nationality, levels of compassion and psychological impact of a health condition such as FS have the potential to be influenced by differences in participant location. This was initially controlled by originally limiting the study to UK participants, but was eventually expanded worldwide following recruitment difficulties, and was unfortunately not controlled for in analysis, increasing sampling bias and decreasing validity of results. In addition, Cronbach's Alpha scores for individual engagement and action scales for compassion to self and others demonstrated reduced reliability of these measures for the current sample, potentially influencing findings.

Future research

The present study was the first to explore the flow of compassion in PwFS. Considering the small but significant moderating effect identified for compassion to self and wellbeing, this study provides some evidence for offering compassion-based therapies as potentially beneficial interventions for managing the psychological impact of FS. It would be beneficial for future research to expand the current study, using further control and a larger sample size to find evidence for the remaining flows of compassion, perhaps using more global measures of QoL and

measures of compassion to self and others of increased reliability to attempt to replicate results. However, based on this research alone, pilot studies measuring the effectiveness of CFT, with focus on compassion to self for FS are warranted.

Conclusion

The present study aimed to investigate whether the flow of compassion moderated the relationship between seizure severity and psychological impact, measured via depression, anxiety and stress, mental wellbeing and QoL. A small moderation effect was identified, establishing self-compassion as a moderator for the negative relationship between mental wellbeing and seizure severity. Several predictions were also observed, i.e. worsening stress and anxiety was predicted by a reluctance to accept compassion from others; reduced symptoms of depression and better wellbeing was predicted by self-compassion and accepting compassion from others and QoL was improved by all three flows of compassion. As this study was the first to measure the flow of compassion in a functional seizure population, initial evidence is provided for CFT to be a potential effective intervention for individuals with FS. Considering the study's limitations, larger studies with further controls and adaptations are recommended.

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Part Three: Appendices

Appendix A: Reflective statement

Empirical paper

As I sit down to begin to write this statement, I notice that reflecting on a project spanning three years feels not an easy task. But I am prepared to give it a go. Prepared to notice and sit with the emotions that may arise; and as much as I will attempt to be present to write this statement, I am aware that reflection may lead into some rumination about difficulties that have arisen and my management of those. But I can also provide myself compassion, by restoring my appreciation of the project being a learning process- and I can confidently say I have learned a lot- about myself as a professional, as a researcher, and as a human being as well as a person with seizures. I would like to write this statement as a story, as a small autobiography if you will, of my journey throughout the research project process. I would also like to take the opportunity to be as open, and reflective as possible, about my journey, as I hope it will feel somewhat therapeutic to allow my thoughts and emotions to flow onto the page, and I can read back through in years to come to remind myself of how I reached the end of the most turbulent journey I have been on thus far.

Let us begin with some context. My journey with functional seizures begins at around 14 years of age, where intense migraines turned into fainting episodes, then turning into convulsive seizures. I would need many hands to count the ambulance journeys and A&E trips in my adolescent and university years, which were not helped by my excessive clumsiness. Several outpatient referrals, food diaries, medical professionals not knowing what on earth was wrong later, I was diagnosed with non-epileptic attack disorder (NEAD; I will return to the terminology dilemma later) at the ripe age of 18. Initial emotions at diagnosis included relief and reprieve (partly because I had already self-diagnosed myself via Google, and I have an objectionable trait of needing to be right), but these were soon followed by apprehension and concern of the future. As

at the time, and in many services still, the only available treatment was neuropsychology at a 2-year waiting list, of which the neurologist kindly advised, was pointless to be added to. Now, this did throw my 18-year-old, undergraduate psychology student self, as the opportunity to work with another psychologist sounded like one not to be missed, but, like the people-pleaser I continue to be, I took the advice and went on my merry way, beginning my journey in seizure self-management.

Fast forward several years, where I gained my place on the doctorate, and begun the process of conceiving an idea for my research project. My undergraduate research project focused on the concept of mental toughness, applying it to the mental health experiences of university students. I thoroughly enjoyed this project, and at the time connected to the idea of developed resilience predicting improved mental health. As such, I desired to continue the research, investigating the concept with a different population, such as in frontline workers. However, as we were required to develop three separate potential thesis ideas, I begun to explore what was pertinent for me in a research project, asking myself questions such as “what will keep me engrossed and enthusiastic for three years?”. I realised through this personal exploration, that topics that meant something personal to me, that I was connected with, were the ideal. Thus, commenced the formation of the current project. I can vividly recall the emotional process of initially scoping the literature- I was reading papers that validated all of my experiences of my condition: literature reviews compiling individuals’ experiences and subsequent thoughts and emotions that matched my own, articles which conceptualised models of the risk factors and triggers for episodes and websites that detailed my symptoms. I learned what functional neurological disorder was for the first time (considering it is a condition I live with!). I no longer felt an alien with my condition. Even though I had not (yet) met or spoke to any fellow sufferers, I already felt a part of a community, and I finally had concrete evidence to put an end to my self-

gaslighting. My position also became real throughout this process. I was in awe of my future capabilities, of the powerful voice I now had as a training psychologist, as a researcher- I could actually help make a difference in the support received.

The idea of researching compassion in functional seizures came as a lightbulb moment whilst meandering through the literature. Although I did not know much about compassion-focused ideas at this stage, the idea somehow seemed to connect. Once agreeing on the feasibility of the project in supervision, I recall trying to read introductory papers and books around CFT, compassionate mind training and their origins, and my brain being completely frazzled by the theory behind the model.

A crucial part of the development of the project was developing a consensus of terminology. Throughout the project, an internal battle has continued around wanting to connect with the label based on my own experiences, but also wanting to keep up-to-date with the literature. I was diagnosed with NEAD, which was the only term I was initially aware of, and is what is continued to be mostly used in services. However, most of the literature in the previous decade-or-so uses the term PNES (psychogenic nonepileptic seizures), as such, it is the term I used in my first research proposal. However, this didn't feel quite right, and I found the study by Aasdi-Pooya et al. (2020) really insightful into the different labels, and which is currently fellow patients' preferred term. From this, I decided to remove the term 'psychogenic', understanding that not all patients connect with psychological processes precipitating or predisposing their seizures, yet still felt a strong connecting to my diagnostic term, hence settling on 'nonepileptic seizures (NES)'. A year or-so later, deep into data collection, I was reminded of the term 'functional seizures', which was indeed the agreed term in the Aasdi-Pooya study. As I was advised by a prolific researcher in the field and an organisation aiding my recruitment, it felt fitting and the right time to adapt, and finalise the project with the term 'functional seizures'.

Recruitment was certainly the most demanding and depleting aspect of the research journey, taking around eight months to reach the necessary number of participants. On reflection, I most likely set my expectations for the smoothness of the process too high, as it did take several months to receive ethical approvals for organisations to advertise the study. Nevertheless, without the support of FND organisations, I would not have reached all 245 of my participants- of which I will be forever grateful. There were certainly peaks and troughs in the data collection process, reflected by changes in methods such as using paid advertisement on social media and expanding from UK-based to international recruitment. The troughs certainly felt defeating, and I frequently felt drained by spending research days finding and advertising in new locations, and emailing fellow researchers, or leads of organisations, (what felt like) begging them to aid with recruitment. Receiving negative, personal comments on Twitter around my competence as a researcher was not easy to manage either, and it took some personal strength not to take the difficulties I was facing personally, and adopting skills of compassion toward myself and my abilities. The day I finally reached my goal number of participants is one that will stick out throughout the remainder of my career- as I had proved to myself that my determination, my endeavour was the reason why I had reached such a high number of people from all over the world. A feat that once felt impossible was achieved, and was, and still is, a huge accomplishment.

The challenge did not end there though, with the prospect of analysing the data looming over. I can confirm this element of the process was the most draining, taking longer than initially expected. However, seeing the final result, knowing meaningful findings have come out of this piece of work makes it all worthwhile.

Systematic literature review

I found the undertaking of the SLR rather overwhelming. Even though it is stressed it is a lengthy operation, the many elements of the project and the time that is needed to dedicate to each part did come as a surprise. Conceptualising a topic and a research question was the first component that took a considerable amount of time, as I had originally desired to focus on the broader topic of FNDs, however the ideas that my supervisors and I felt were feasible, had already been conducted, so the continuous process of returning back to the drawing board felt frustrating. This frustration continued when a question was finally agreed, and papers were located, it took even longer to clarify exclusionary criteria to provide a small number of papers that felt practical to review. As a person who finds organisation, planning, structure, etc., difficult, the SLR was a task that did not come easy. So, when it came to documenting the process for the results, and even locating each paper to form the PRISMA diagram, I easily became very stressed, and self-critical at my inability at creating a system, at organising my work. As I did try, for example by creating a folder on the database at each selection stage, and creating a log of each excluded paper, but I found I did not do this very well, making me more confused and creating more work for myself later on. My impatience and short attention span were also revealed during this project. Keeping on task through the lengthy, rather laborious processes of data extraction and quality assessments was not easy, and again found I created myself more work later on when it came to creating tables and writing my results, by not completing each task fully initially. As such, the SLR is a project where I learned a lot about myself as a researcher. It would be natural to be self-critical around the difficulties I faced, and there were times where I did internalise comments I received on Twitter in relation to my inabilities of organisation etc., creating further anxiety about my future as a psychologist. However, as I mentioned at the start of this reflection, I am just as able to connect to self-compassionate thoughts, reminding myself the SLR is not an easy feat, and is not one that is typically conducted by just one person. As such, I feel considering the large undertaking of the

project and it was the first one I have written, I can say I am proud of the piece of work I have produced.

In conclusion

This research project has been one of the most, crucial part of my journey with FS/FND. The opportunities this has provided me, originally felt out of my wildest dreams. Without this, I would not have connected with individuals across the world, would not have shared my ideas at an international conference, and would not have had the courage to deliver specific training of FS/FND, sharing my experiences to several NHS organisations. This journey has not only enabled me to accept my condition as a part of me to be proud of, but it has also inspired me to not allow my journey to disappear into the ether and become a distant memory. My journey with FND as a researcher, as a professional, will not end with this project. There is so much more work to be done in the understanding and in the treatment of functional neurological disorders, and I cannot wait to use my personal knowledge and experience to help others, and be a part of the change in one way, shape, or form. It may be a cliché, but the quote “if the version of you from 5 years ago could see you right now, they would be so proud. Keep going” has been my beacon in the darkest times of the doctorate. And it will continue to be throughout qualified life, as it is so, damn, true.

Appendix B: Epistemological statement

Acknowledging the researcher's adopted epistemological and ontological positions is essential, as studies' methodology are guided by the assumptions and biases conceived by these ideas [1]. Therefore, the aim of this statement is to illustrate the stances taken by the current researcher.

Ontology is the study of existence and the nature of reality and being [2]. A realist ontological stance assumes there is a static truth, measured objectively [3], whereas a relativist position believes truth is subjective and contextual, bound by experience [4]. However, the current research adopted a critical realist stance, an alternative to these paradoxical positions, believing in the social constructionism of reality and the importance of the human experience, while acknowledging there exists a regular real world [3] [5]. This position allows for the validity and credibility of research, by method of triangulation [3]. This was adopted by using objective methods to measure compassion, psychological wellbeing and seizure severity in the empirical paper, and psychological outcomes following intervention in the literature review, whilst acknowledging these are not concepts that hold a certain truth or fact as they are bound by individual experience.

Epistemology relates to how knowledge becomes known and is determined by the ontological position [2]. As such, the current research methodology was informed by a postpositivist stance. Although quantitative methodologies, the methodology undertaken by the current study, is typically underpinned by a positivist stance, this would assume independence of the research and researcher. Instead, a modified dualist approach understands it is not entirely possible to remain absolutely distanced, acknowledging the potential of the researcher's own experiences and knowledge potentially influencing observations. In addition, a positivist approach would involve the collection of well-founded, objective data, when a postpositivist position

understands the study of human beings is distinctive to that of inanimate objects [6]. This position was supported by the researcher's personal experience with functional seizures. Although this inspired, and has helped guide, the direction of the research, the potential influence of the researcher's biases and assumptions on the project was considered and managed appropriately throughout. This approach was undertaken in the current research by not permitting certainty when interpreting findings, aiming to falsify its hypothesis, rather than verify. In addition, although a quantitative method was also focused on in the literature review, the use of a narrative synthesis approach instead of a meta-analysis further demonstrated the post-positivist position by exploring potential factors rather than producing fixed outcomes.

To summarise, a critical realist ontological and postpositivist position informed the current research's quantitative methodology measuring the individual experiences of the moderating effect of the flow of compassion on the relationship between seizure severity and psychological distress.

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Appendix C: Guideline for authors for the empirical paper for submission to European Journal of Epilepsy: Seizure

1.1 Peer-reviewed articles

a. Full reviews.

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

b. Focused reviews.

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

c. Full-length original research articles.

The body of the text of these articles should be limited in length to 4,000 words, and there should be a maximum of 6 figures or tables. Additional figures, tables and other material (such as associated videos) can be submitted as online only Supporting Information (see section 'preparation of manuscripts' for further

details). Full length research articles should be preceded by an abstract. The body of the text of the article should be clearly structured into 1) Introduction, 2) Methods 3) Results, 4) Discussion, 5) Conclusion and 6) References.

d. Short communications.

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

e. Case reports (Clinical Letters), see also ***Interactive Case Insights*** below Seizure will also publish particularly instructive case reports in the format of Clinical Letters. Clinical Letters will not be preceded by an abstract. The word count is strictly limited to 1,000 words excluding title page information, references, and any figure or table legends. Clinical Letters can only include a maximum of 4 references and 2 figures or tables (combined), authors may include additional reading as supplementary material.

f. Letters to the Editor

Letters containing critical assessment of papers recently published in the *Seizure - European Journal of Epilepsy* will be considered for publication in the correspondence section. Letters should not exceed 1,000 words including references as necessary, one table or one figure. Letters should be typed in

double spacing, should have a heading and no abbreviations. If related to a previously published article, the article should be identified by title, author(s), and volume/page numbers. All letters are subject to editorial review. At the Editor's discretion, a letter may be sent to authors of the original paper for comment, and both letter and reply may be published together.

1.2 Editorially-reviewed material

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

1.3 Supplements / Special Editions

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

ideas. Special editions of Seizure would be expected to contain the same kind of manuscripts which are published in normal editions.

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You can use this list to carry out a final check of your submission before you send it to the journal for review. Please check the relevant section in this Guide for Authors for more details.

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• All tables (including titles, description, footnotes)

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Graphical Abstracts / Highlights files (where applicable)

Supplemental files (where applicable)

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Reporting guidance

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Sex generally refers to a set of biological attributes that are associated with physical and physiological features (e.g., chromosomal genotype, hormonal levels, internal and external anatomy). A binary sex categorization (male/female) is usually designated at birth ("sex assigned at birth"), most often based solely

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Divide your article into clearly defined sections. Each subsection is given a brief heading. Each heading should appear on its own separate line. Subsections

should be used as much as possible when cross-referencing text: refer to the subsection by heading as opposed to simply 'the text'.

Introduction

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

Material and methods

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

Theory/calculation

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

Results

Results should be clear and concise.

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

Discussion

This should explore the significance of the results of the work, not repeat them. Avoid extensive citations and discussion of published literature. Speculative discussion is not discouraged, but the speculation should be based on the data presented and identified as such.

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

Conclusions

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

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

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The EQUATOR Network (https://www.equator-network.org/) is an excellent resource for key reporting guidelines, checklists, and flow diagrams. These guidelines should be especially useful for Seizures' authors.

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Randomized Controlled Trials - CONSORT - Consolidated Standards of Reporting Trials

Observational Studies - STROBE - Strengthening the Reporting of Observational studies in Epidemiology

Systematic Review of Controlled Trials - PRISMA - Preferred Reporting Items for Systematic Reviews and Meta-Analyses

Study of Diagnostic accuracy/assessment scale - STARD - Standards for the Reporting of Diagnostic Accuracy Studies

For psychometric studies the editors recommend either the COSMIN or GRRAS guideline, though the final choice is up to the author.

During the submission process when you are prompted to state which checklist is used please type it into the provided text box for your manuscript or type Not Applicable if your paper is an Editorial, Letter to the Editor, Book Review etc. For the mandatory article types the system will ensure that you upload the file using the "Supporting File" file type, you should upload the appropriate checklist and flow diagram. IT IS PERMISSIBLE TO ADD A COLUMN OR SPACE TO THE CHECKLIST THAT SPECIFIES WHERE IN THE MANUSCRIPT EACH COMPONENT HAS BEEN FOLLOWED AND USE THAT FOR YOUR UPLOAD. YOU MAY NEED TO DO THIS FOR STROBE AS WELL AS OTHERS. THE LATEST STROBE FORM IS AVAILABLE HERE

Essential title page information

• ***Title.*** Concise and informative. Titles are often used in information-retrieval systems. Avoid abbreviations and formulae where possible.

• ***Author names and affiliations.*** Please clearly indicate the given name(s) and

family name(s) of each author and check that all names are accurately spelled. You can add your name between parentheses in your own script behind the English transliteration. Present the authors' affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lower-case superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e-mail address of each author.

• ***Corresponding author.*** Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. This responsibility includes answering any future queries about Methodology and Materials. **Ensure that the e-mail address is given and that contact details are kept up to date by the corresponding author.**

• ***Present/permanent address.*** If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main, affiliation address. Superscript Arabic numerals are used for such footnotes.

Correct author name format

To prevent confusion please ensure that all author names are listed in the following format; first (Christian) name first and the last name (Surname/Family)

last. This is specified because Spain, China and some other countries often write them differently and this causes confusion with databases like MEDLINE.

Highlights

Highlights are mandatory for this journal as they help increase the discoverability of your article via search engines. They consist of a short collection of bullet points that capture the novel results of your research as well as new methods that were used during the study (if any). Please have a look at the example Highlights.

Highlights should be submitted in a separate editable file in the online submission system. Please use 'Highlights' in the file name and include 3 to 5 bullet points (maximum 85 characters, including spaces, per bullet point).

Abstract

A concise and factual abstract is required. The abstract should state briefly the purpose of the research, the principal results and major conclusions. An abstract is often presented separately from the article, so it must be able to stand alone. For this reason, References should be avoided, but if essential, then cite the author(s) and year(s). Also, non-standard or uncommon abbreviations should be avoided, but if essential they must be defined at their first mention in the abstract

itself.

Abstracts for regular articles and short communications should be structured, using the subheadings purpose, methods, results, conclusion. For reviews, the abstract does not need to follow this structure. They should be no longer than 250 words. Case reports (Clinical Letters) do not need to be preceded by an abstract.

Graphical abstract

Although a graphical abstract is optional, its use is encouraged as it draws more attention to the online article. The graphical abstract should summarize the contents of the article in a concise, pictorial form designed to capture the attention of a wide readership. Graphical abstracts should be submitted as a separate file in the online submission system. Image size: Please provide an image with a minimum of 531 × 1328 pixels (h × w) or proportionally more. The image should be readable at a size of 5 × 13 cm using a regular screen resolution of 96 dpi. Preferred file types: TIFF, EPS, PDF or MS Office files. You can view Example Graphical Abstracts on our information site.

Please note that the *Highlights* section above only applies to **Full Length Articles** and **Reviews**.

Keywords

Immediately after the abstract, provide a maximum of 6 keywords, using British spelling and avoiding general and plural terms and multiple concepts (avoid, for example, 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible. These keywords will be used for indexing purposes.

Abbreviations

Define abbreviations that are not standard in this field in a footnote to be placed on the first page of the article. Such abbreviations that are unavoidable in the abstract must be defined at their first mention there, as well as in the footnote. Ensure consistency of abbreviations throughout the article.

Acknowledgements

Collate acknowledgements in a separate section at the end of the article before the references and do not, therefore, include them on the title page, as a footnote to the title or otherwise. List here those individuals who provided help during the research (e.g., providing language help, writing assistance or proof reading the article, etc.).

Formatting of funding sources

List funding sources in this standard way to facilitate compliance to funder's requirements:

Funding: This work was supported by the National Institutes of Health [grant numbers xxxx, yyyy]; the Bill & Melinda Gates Foundation, Seattle, WA [grant number zzzz]; and the United States Institutes of Peace [grant number aaaa].

It is not necessary to include detailed descriptions on the program or type of grants and awards. When funding is from a block grant or other resources available to a university, college, or other research institution, submit the name of the institute or organization that provided the funding.

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Follow internationally accepted rules and conventions: use the international

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Please submit math equations as editable text and not as images. Present simple formulae in line with normal text where possible and use the solidus (/) instead of a horizontal line for small fractional terms, e.g., X/Y. In principle, variables are to be presented in italics. Powers of e are often more conveniently denoted by exp. Number consecutively any equations that have to be displayed separately from the text (if referred to explicitly in the text).

Footnotes

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Electronic artwork

General points

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• Number the illustrations according to their sequence in the text.

• Use a logical naming convention for your artwork files.

• Indicate per figure if it is a single, 1.5 or 2-column fitting image.

• For Word submissions only, you may still provide figures and their captions, and tables within a single file at the revision stage.

• Please note that individual figure files larger than 10 MB must be provided in separate source files.

A detailed guide on electronic artwork is available.

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Formats

Regardless of the application used, when your electronic artwork is finalized, please 'save as' or convert the images to one of the following formats (note the resolution requirements for line drawings, halftones, and line/halftone combinations given below):

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minimum of 300 dpi.

TIFF (or JPG): Bitmapped line drawings: use a minimum of 1000 dpi.

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• Supply files that are optimized for screen use (e.g., GIF, BMP, PICT, WPG); the resolution is too low.

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• Submit graphics that are disproportionately large for the content.

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Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules and shading in table cells.

References

Citation in text

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

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As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

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This journal encourages you to cite underlying or relevant datasets in your manuscript by citing them in your text and including a data reference in your

Reference List. Data references should include the following elements: author name(s), dataset title, data repository, version (where available), year, and global persistent identifier. Add [dataset] immediately before the reference so we can properly identify it as a data reference. The [dataset] identifier will not appear in your published article.

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Where a preprint has subsequently become available as a peer-reviewed publication, the formal publication should be used as the reference. If there are preprints that are central to your work or that cover crucial developments in the topic, but are not yet formally published, these may be referenced. Preprints should be clearly marked as such, for example by including the word preprint, or the name of the preprint server, as part of the reference. The preprint DOI should also be provided.

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There are no strict requirements on reference formatting at submission. References can be in any style or format as long as the style is consistent. Where applicable, author(s) name(s), journal title/book title, chapter title/article title, year of publication, volume number/book chapter and the article number or pagination must be present. Use of DOI is highly encouraged. The reference style used by the journal will be applied to the accepted article by Elsevier at the proof stage. Note that missing data will be highlighted at proof stage for the author to correct. If you do wish to format the references yourself they should be arranged according to the following examples:

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Text: Indicate references by number(s) in square brackets in line with the text. The actual authors can be referred to, but the reference number(s) must always be given.

List: Number the references (numbers in square brackets) in the list in the order in which they appear in the text.

Examples:

Reference to a journal publication:

[1] Van der Geer J, Hanraads JAJ, Lupton RA. The art of writing a scientific article. J Sci Commun 2010;163:51–9. https://doi.org/10.1016/j.Sc.2010.00372.

Reference to a journal publication with an article number:

[2] Van der Geer J, Hanraads JAJ, Lupton RA. The art of writing a scientific article. Heliyon. 2018;19:e00205. https://doi.org/10.1016/j.heliyon.2018.e00205

Reference to a book:

[3] Strunk Jr W, White EB. The elements of style. 4th ed. New York: Longman; 2000.

Reference to a chapter in an edited book:

[4] Mettam GR, Adams LB. How to prepare an electronic version of your article. In: Jones BS, Smith RZ, editors. Introduction to the electronic age, New York: E-Publishing Inc; 2009, p. 281–304.

Reference to a website:

[5] Cancer Research UK. Cancer statistics reports for the UK, http://www.cancerresearchuk.org/aboutcancer/statistics/cancerstatsreport/; 2003 [accessed 13 March 2003].

Reference to a dataset:

[dataset] [6] Oguro M, Imahiro S, Saito S, Nakashizuka T. Mortality data for Japanese oak wilt disease and surrounding forest compositions, Mendeley Data, v1; 2015. https://doi.org/10.17632/xwj98nb39r.1.

Note shortened form for last page number. e.g., 51–9, and that for more than 6 authors the first 6 should be listed followed by 'et al.' For further details you are referred to 'Uniform Requirements for Manuscripts submitted to Biomedical Journals' (J Am Med Assoc 1997;277:927–34) (see also Samples of Formatted References).

Journal abbreviations source

Journal names should be abbreviated according to the List of Title Word Abbreviations.

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Include interactive data visualizations in your publication and let your readers interact and engage more closely with your research. Follow the instructions here to find out about available data visualization options and how to include them with your article.

Supplementary material

Supplementary material such as applications, images and sound clips, can be published with your article to enhance it. Submitted supplementary items are published exactly as they are received (Excel or PowerPoint files will appear as such online). Please submit your material together with the article and supply a concise, descriptive caption for each supplementary file. If you wish to make changes to supplementary material during any stage of the process, please make sure to provide an updated file. Do not annotate any corrections on a previous version. Please switch off the 'Track Changes' option in Microsoft Office files as these will appear in the published version.

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This journal encourages and enables you to share data that supports your research publication where appropriate, and enables you to interlink the data with your published articles. Research data refers to the results of observations or experimentation that validate research findings, which may also include software, code, models, algorithms, protocols, methods and other useful materials related to the project.

Below are a number of ways in which you can associate data with your article or make a statement about the availability of your data when submitting your

manuscript. If you are sharing data in one of these ways, you are encouraged to cite the data in your manuscript and reference list. Please refer to the "References" section for more information about data citation. For more information on depositing, sharing and using research data and other relevant research materials, visit the research data page.

Data linking

If you have made your research data available in a data repository, you can link your article directly to the dataset. Elsevier collaborates with a number of repositories to link articles on ScienceDirect with relevant repositories, giving readers access to underlying data that gives them a better understanding of the research described.

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Data statement

To foster transparency, we encourage you to state the availability of your data in your submission. This may be a requirement of your funding body or institution. If your data is unavailable to access or unsuitable to post, you will have the opportunity to indicate why during the submission process, for example by stating that the research data is confidential. The statement will appear with your published article on ScienceDirect. For more information, visit the Data Statement page.

Interactive Case Insights

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Appendix D: Guideline for authors for the empirical paper for submission to Journal of

Neuropsychology

NP AUTHOR GUIDELINES

Sections

1. SUBMISSION

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New submissions should be made via the **Research Exchange submission portal**. You may check the status of your submission at any time by logging on to submission.wiley.com and clicking the "My Submissions" button. For technical help with the submission system, please review our FAQs or contact **submissionhelp@wiley.com**.

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The Journal of Neuropsychology publishes original contributions to scientific knowledge in neuropsychology including:

- clinical and research studies with neurological, psychiatric and psychological patient populations in all age groups
- behavioural or pharmacological treatment regimes
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The following types of paper are invited:

- papers reporting original empirical investigations
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- review articles, which need not be exhaustive, but which should give an interpretation of the state of research in a given field and, where appropriate, identify its clinical implications
- brief reports and comments
- case reports
- fast-track papers (included in the issue following acceptation) reaction and rebuttals (short reactions to publications in JNP followed by an invited rebuttal of the original authors)
- special issues.

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

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For all articles, the journal mandates the CRediT (Contribution Roles Taxonomy)—more information is available on our **Author Services** site.

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Please provide an abstract which gives a concise statement of the intention, results or conclusions of the article. The abstract should not include any sub-headings.

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Keywords

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Acknowledgments

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- References;
- Tables (each table complete with title and footnotes);
- Figure legends: Legends should be supplied as a complete list in the text. Figures should be uploaded as separate files (see below)
- Statement of Contribution.

Supporting information should be supplied as separate files. Tables and figures can be included at the end of the main document or attached as separate files but they must be mentioned in the text.

- As papers are double-anonymous peer reviewed, the main text file should not include any information that might identify the authors. Please do not mention the authors' names or affiliations and always refer to any previous work in the third person.
- The journal uses British/US spelling; however, authors may submit using either option, as spelling of accepted papers is converted during the production process.

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Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

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Click here for the basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.

Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

Supporting Information

Supporting information is information that is not essential to the article, but provides greater depth and background. It is hosted online and appears without editing or typesetting. It may include tables, figures, videos, datasets, etc.

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General Style Points

For guidelines on editorial style, please consult the **APA Publication Manual** published by the American Psychological Association. The following points provide general advice on formatting and style.

- **Language:** Authors must avoid the use of sexist or any other discriminatory language.
- **Abbreviations:** In general, terms should not be abbreviated unless they are used repeatedly and the abbreviation is helpful to the reader. Initially, use the word in full, followed by the abbreviation in parentheses. Thereafter use the abbreviation only.
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- **Effect size:** In normal circumstances, effect size should be incorporated.
- **Numbers:** numbers under 10 are spelt out, except for: measurements with a unit (8mmol/l); age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).

Wiley Author Resources

Manuscript Preparation Tips: Wiley has a range of resources for authors preparing manuscripts for submission available **here.** In particular, we encourage authors to consult Wiley's best practice tips on **Writing for Search Engine Optimization**.

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Also, check out our resources for **Preparing Your Article** for general guidance and the **BPS Publish with Impact infographic** for advice on optimizing your article for search engines.

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Peer Review and Acceptance

Except where otherwise stated, the journal operates a policy of anonymous (double-anonymous) peer review. Please ensure that any information which may reveal author identity is anonymized in your submission, such as institutional affiliations, geographical location or references to unpublished research. We also operate a triage process in which submissions that are out of scope or otherwise inappropriate will be rejected by the editors without external peer review. Before submitting, please read **the terms and conditions of submission** and the **declaration of competing interests**.

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

- the content of the paper falls within the scope of the Journal
- the methods and/or sample size are appropriate for the questions being addressed
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The *Journal of Neuropsychology* is committed to a fast and efficient turnaround of papers, aiming to complete the review process in under two months.

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We encourage authors to adhere to the APA Style Journal Article Reporting Standards for:

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Funding

Authors should list all funding sources in the Acknowledgments section. Authors are responsible for the accuracy of their funder designation. If in doubt, please check the Open Funder Registry for the correct nomenclature: **https://www.crossref.org/services/funder-registry/**

Authorship

All listed authors should have contributed to the manuscript substantially and have agreed to the final submitted version. Authorship is defined by the criteria set out in the APA Publication Manual:

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In some cases, despite the authors' best efforts, some or all data or materials cannot be shared for legal or ethical reasons, including issues of author consent, third party rights, institutional or national regulations or laws, or the nature of data gathered. In such cases, authors must inform the editors at the time of submission. It is understood that in some cases access will be provided under restrictions to protect confidential or proprietary information. Editors may grant exceptions to data access requirements provided authors explain the restrictions on the data set and how

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9. EDITORIAL OFFICE CONTACT DETAILS

For help with submissions, please contact: Hannah Wakley, Associate Managing Editor (**jnp@wiley.com**) or phone +44 (0) 116 252 9504.

Appendix E: Data extraction form

Study Characteristics	
Author(s):	
Year:	
Title:	
Design:	
Aim:	
Participant characteristics	
Country of residence:	
Mean age:	
Gender:	
How diagnosed:	
Length of time since onset: (changed from diagnosis following several papers reporting this not diagnosis)	
Sample size:	
Current mental health difficulties:	
Comorbidities:	
Intervention characteristics	
Type of intervention:	
Duration:	
Mode of delivery:	
Deliverer:	
Trial characteristics	
Inclusion/ exclusion criteria:	
Study recruitment process:	
Randomisation?:	
Control/comparison group?:	
Setting:	
Outcome characteristics	
Mental health outcome measure:	
When measured:	
Analyses:	
Main findings:	

Appendix F: Quality checklist

Table 5.

The Effective Public Health Practice Project quality assessment tool [52].

A) <u>Selection Bias</u>							
(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?	1 Very likely	2 Somewhat likely	3 Not likely	4 Can't tell			
(Q2) What percentage of selected individuals agreed to participate?	1 80-100%	2 60-79%	3 Less than 60%	4 Not applicable	5 can't tell		
Rate this section:	**1 Strong**	**2 Moderate**	**3 Weak**				
B) <u>Study Design</u>							
Indicate the study design:	1 RCT	2 Controlled Clinical Trial	3 Cohort Analytic	4 Case-Control	5 Cohort	6 Interrupted time series	7 Other	8 Can't tell
Was the study described as randomised? If no, go to component C	No	Yes					
If Yes, was the method of randomisation described?	No	Yes					
If yes, was the method appropriate?	No	Yes					
Rate this section:	**1 Strong**	**2 Moderate**	**3 Weak**				
C) Confounders							
Q1) Were there important differences between groups prior the intervention?	1 Yes	2 No	3 Can't tell				

The following are examples of confounders:	1 Race	2 Sex	3 Marital status/family	4 Age	5 SES	6 Education	7 Health Status	8 Pre-intervention score on outcome measure

If yes, indicate the percentage of relevant confounders that were controlled (either by stratification, matching or in the analysis)	1 80-100%	2 60-79%	<60%	4 Can't tell

Rate this section	**1 Strong**	**2 Moderate**	**3 Weak**
D) Blinding			
(Q1) Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?	1 Yes	2 No	3 Can't tell
(Q2) Were the study participants aware of the research question?	1 Yes	2 No	3 Can't tell
Rate this section	**1 Strong**	**2 Moderate**	**3 Weak**
<u>Data Collection Methods</u>			
(Q1) Were data collection tools shown to be valid?	1 Yes	2 No	3 Can't tell
(Q2) Were data collection tools shown to be reliable?	1 Yes	2 No	3 Can't tell
Rate this section	**1 Strong**	**2 Moderate**	**3 Weak**
<u>Withdrawals and Drop-Outs</u>			

Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?	1 yes	2 no	3 Can't tell	4 Not applicable

Indicate the percentage of participants completing the study	1 80-100%	2 60-79%	3 <60%	4 Can't tell	5 Not applicable

Rate this section	**1 Strong**	**2 Moderate**	**3 Weak**	**Not applicable**
<u>Intervention Integrity</u>				

(Q1) What percentage of participants received the allocated intervention or exposure of interest?	1 80-100%	2 60-79%	3 Less than 60%	4 Can't tell
(Q2) Was the consistency of the intervention measured?	1 Yes	2 No	3 Can't tell	
(Q3) Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?	1 Yes	2 No	3 Can't tell	
Analyses				
(Q1) Indicate the unit of allocation	Community	Organisation/institution	Practice/office	individual
(Q2) Indicate the unit of analysis	Community	Organisation/institution	Practice/office	individual
(Q3) Are the statistical methods appropriate for the study design?	1 Yes	2 No	3 Can't tell	
(Q4) Is the analysis performed by intervention allocation status (i.e.- intention to treat) rather than intervention received?	1 Yes	2 No	3 Can't tell	

Appendix G: Ethical and Health Research Authority approval

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PRIVATE AND CONFIDENTIAL
Ms Amy Utting
Faculty of Health Sciences
University of Hull
Via email

Tuesday 28th June 2022

Dear Amy

REF FHS438 - Investigating the Role of Compassion in the Psychological Impact of Non-Epileptic Seizures

Thank you for your responses to the points raised by the Faculty of Health Sciences Research Ethics Committee.

Given the information you have provided I confirm approval by Chair's action.

Please refer to the Research Ethics Committee web page for reporting requirements in the event of any amendments to your study.

Should an Adverse Event need to be reported, please complete the Adverse Event Form and send it to the Research Ethics Committee FHS-ethicssubmissions@hull.ac.uk within 15 days of the Chief Investigator becoming aware of the event.

I wish you every success with your study.

Yours sincerely

Professor Liz Walker
Chair, FHS Research Ethics Committee

UNIVERSITY OF HULL

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PRIVATE AND CONFIDENTIAL
Amy Utting
Faculty of Health Sciences
University of Hull
Via email

Tuesday 2nd August 2022

Dear Amy

REF FHS438 - Investigating the Role of Compassion in the Psychological Impact of Non-Epileptic Seizures

Thank you for your notice of amendment. Given the information you have provided I confirm approval by Chair's action.

Please refer to the Research Ethics Committee web page for reporting requirements in the event of any further amendments to your study.

Should an Adverse Event need to be reported, please complete the Adverse Event Form and send it to the Research Ethics Committee FHS-ethicssubmissions@hull.ac.uk within 15 days of the Chief Investigator becoming aware of the event.

I wish you every success with your study.

Yours sincerely

Professor Maureen Twiddy
Chair, FHS Research Ethics Committee

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PRIVATE AND CONFIDENTIAL
Amy Utting
Faculty of Health Sciences
University of Hull
Via email

Monday 3rd October 2022

Dear Amy,

REF FHS 438 - Investigating the Role of Compassion in the Psychological Impact of Non-Epileptic Seizures

Thank you for your notice of amendment. Given the information you have provided I confirm approval by Chair's action.

Please refer to the Research Ethics Committee web page for reporting requirements in the event of any further amendments to your study.

Should an Adverse Event need to be reported, please complete the Adverse Event Form and send it to the Research Ethics Committee FHS-ethicssubmissions@hull.ac.uk within 15 days of the Chief Investigator becoming aware of the event.

I wish you every success with your study.

Yours sincerely

Professor Maureen Twiddy
Chair, FHS Research Ethics Committee

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PRIVATE AND CONFIDENTIAL
Amy Utting
Faculty of Health Sciences
University of Hull
Via email

Thursday 20th October 2022

Dear Amy,

REF FHS 438 - Investigating the Role of Compassion in the Psychological Impact of Non-Epileptic Seizures

Thank you for your notice of amendment. Given the information you have provided I confirm approval by Chair's action.

Please refer to the Research Ethics Committee web page for reporting requirements in the event of any further amendments to your study.

Should an Adverse Event need to be reported, please complete the Adverse Event Form and send it to the Research Ethics Committee FHS-ethicssubmissions@hull.ac.uk within 15 days of the Chief Investigator becoming aware of the event.

I wish you every success with your study.

Yours sincerely

Professor Maureen Twiddy
Chair, FHS Research Ethics Committee

UNIVERSITY OF HULL

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Appendix H: Information sheet

INFORMATION SHEET FOR PARTICIPANTS

Title of study: Investigating the Role of Compassion in the Psychological Impact of Non-Epileptic Seizures/ Functional Seizures

We would like to invite you to participate in a research project which looks into the role compassion plays in the mental health impact of living with, and being diagnosed with, functional seizures/ non-epileptic seizures (NES).

This study is a research project forming part of my Clinical Psychology Doctorate research at the University of Hull.

Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask me if there is anything that is not clear or if you would like more information by sending an email to a.l.utting-2017@hull.ac.uk

What is the purpose of the study?

The purpose of this study is to further understand the relationship between functional seizure/ NES severity and its impact on mental health. Research suggests the mental health impact of functional seizure/ NES may be unique, as individuals have increased levels of self-criticism, shame and self-blame, which in turn may further worsen their condition.
Within psychology research, compassion (accepting compassion from others, providing compassion to others and having self-compassion) has shown to decrease these feelings of self-criticism, self-blame and shame, therefore improving mental health. However, this has not yet been explored within functional seizures/NES.

It is therefore the aim of this study to investigate the role compassion plays on the impact functional seizures/ NES severity has on mental health.

Why have I been invited to take part?

We have looking for adults aged over 18, who have received a diagnosis of non-epileptic seizures/ functional seizures/ non-epileptic attack disorder (NEAD)/ dissociative seizures/ psychogenic non-epileptic seizures.

Am I eligible to take part?

You are eligible to participate in this study if:

- You are an adult over 18 who has received a diagnosis of functional seizures, non-epileptic seizures (NES) or similar
- You are able to read and understand the English language
- You do not have a co-morbid diagnosis of epilepsy

- You are not taking anti-epileptic medication (AEDs)

As important as it is that every person who experiences functional seizures/ NES has the right to have their voice heard, unfortunately all of these factors have the potential to impact the study's results.

What will happen if I take part?

The study has been advertised as a link on various organisation's websites or social media pages such as Facebook, Instagram and Twitter. Once you have read through the following information, you will be presented with a consent form on the following page. Here you will be able to decide whether you would like to participate in the research.
If you decide to take part, you will be presented with:

- A demographic questionnaire (questions about your age, gender and length of time since functional seizure/ NES diagnosis)
- a survey about the severity of your seizures. Here, you will be asked to respond to a series of questions on a maximum scale of 0-5 about the most severe seizure you have experienced in the past four weeks. If you have not experienced a seizure in the past four weeks, respond with your most recent seizure.
- Two compassion questionnaires: one asking about your overall experience with compassion on a scale of 0-10 and another asking about your overall experience on a scale of 0-4.
- A questionnaire asking about your experiences with mental health from the past week on a scale of 0-3.
- A survey asking several questions about your general health, and your health within the past four weeks, on a series of scales.
- A short questionnaire asking about your wellbeing over the past two weeks on a scale of 0-5.

An example from the wellbeing questionnaire is "*I've been feeling optimistic about the future".* The requirements of each questionnaire will be further explained when you commence the study. You will be asked to respond to every question as honestly and accurately as possible. Questionnaires may be over a number of pages, so once all questions on that page have been answered, you will be able to move onto the next page. When you have finished the last question, you will be prompted to click a submit button which will submit you answers and contribute your data to the overall research database to be analysed. There will be a save button so you can save your progress, meaning all questionnaires do not have to responded to in one go. You will be able to withdraw from the study at any point while taking part. Taking part will take no more than 30-40 minutes of your time.

Do I have to take part?

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in any way. Once you have read the information sheet, please contact us if you have any questions that will help you make a decision about taking part. If you decide to take part, we will ask you to sign a consent form, which will ask you to confirm you have understood this information and had the opportunity to ask any questions. You will be unable to participate in the study until you have consented.

During taking part, you will be able to withdraw from the study at any point, without providing a reason. However, as your information will be completely anonymous, you will be unable to withdraw your data from the research once you have submitted your responses to the surveys.

What are the possible risks of taking part?

The nature of the questions asked in this study has the potential to cause distress as they ask details about your most severe, recent seizure. For some people, this may trigger a seizure. If you are aware this could be a trigger for a seizure, please **do not** take part in this study. You will also be asked potentially distressing questions about your mental health, wellbeing, health and compassion.
Contact details of sources of support will be provided at the end of the study should taking part cause distress. It is suggested you take a picture or a screenshot of the sources of support, as they will not be able to download from the survey website.

What are the possible benefits of taking part?

We are unable to promise any direct benefits of taking part in this study. However, the information you provide will be beneficial in helping us further understand the relationship between functional seizures/ NES and its impact on mental health. This may have further potential benefits on the research into future treatment options for those with functional seizures/ NES.

How will we use information about you?

Your data will be processed in accordance with General Protection Regulation Act, 2016 (GDPR):

- The survey will not ask for any personally identifiable information- all participants' data will remain anonymous throughout the entirety of the research.
- All data gathered will be stored and retained for 10 years as consistent with University of Hull policy.
- Data will be shared with the primary researcher's supervisors, as well as organisations used for recruitment who request a summary of research findings.
- Anonymised data may be used in conference presentations upon the completion of the study
- Data may also be used by future research and so may also be shared anonymously with other researchers.
- Once you have completed the study, your data will be stored safely on the researcher's secure and encrypted laptop meaning the study is also completely confidential.
- The information you provide will help contribute to the results of the study, which will be summarised in a written thesis as part of the researcher's Doctorate in Clinical Psychology. The thesis will be available on the University of Hull's on-line repository https://hydra.hull.ac.uk. The research may also be published in academic journals or presented at conferences.

What are your choices about how your information is used?

While taking part in the study, you can withdraw at any point, and the information you provide will not be saved. However, once you have submitted your responses, your data will not be able to be removed due to the anonymous nature of the research.

Data Protection Statement

The data controller for this project will be the University of Hull. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a 'task in the public interest'.

If you are not happy with the sponsor's response or believe the sponsor processing your data in a way that is not right or lawful, you can complain to the Information Commissioner's Office (ICO) (www.ico.org.uk or 0303 123 1113).

What will happen to the results of the study?

The results of the study will be summarised in a written thesis as part of a Doctorate in Clinical Psychology. The thesis will be available on the University of Hull's on-line repository https://hydra.hull.ac.uk. The research may also be published in academic journals or presented at conferences and be provided to the organisations who have aided with recruitment. If you want to hear about the results of the study then do contact the researcher, Amy Utting, who will be happy to provide you with a written summary of the research.

How is the project being funded?

This study is being funded by the University of Hull, Cottingham Road, Hull, HU6 7RX.

Who has reviewed this study?

Research studies are reviewed by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and been given a favourable opinion by the Faculty of Health Sciences Ethics Committee, University of Hull.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact the researcher using the following contact details.

Amy Utting
E-mail: a.l.utting-2017@hull.ac.uk

What if I have further questions, or if something goes wrong?

If you wish to make a complaint about the conduct of the study, you can contact the University of Hull using the research supervisor's details below for further advice and information, due to COVID-19 restriction contact via email is preferred:

Dr Philip Molyneux
Clinical Psychology
Aire Building
The University of Hull
Cottingham Road
Hull
HU6 7RX
Tel: +44 (0) 1482 464008
Email address: p.molyneux@hull.ac.uk

Sources of support

- Samaritans UK Helpline (24/7) https://www.samaritans.org/how-we-can-help/contact-samaritan/
- MIND (signposting and information service) https://www.mind.org.uk/information-support/helplines/
- FND Hope UK (helpline) https://www.fndhope.org.uk/about-fnd-hope/fnd-hope-uk/uk-telephone-helpline/
- FND Action (UK online support groups) https://www.fndaction.org.uk/facebook-support-groups/

Thank you for reading this information sheet and for considering taking part in this research.

Appendix I: Participant consent form

CONSENT FORM

Title of study: **Investigating the Role of Compassion in the Psychological Impact of Non-Epileptic Seizures**

Name of Researcher: Amy Utting

Name of Supervisor: Dr Philip Molyneux, Dr Tim Alexander

1. I confirm that I have read the information sheet dated 09.06.22 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time until the survey is submitted, without giving any reason, without my legal rights being affected.

3. I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers.

4. I give permission for the collection and use of my data to answer the research question in this study.

5. I have read the information sheet and am of the risk that the study may trigger a seizure. I confirm I do not anticipate this risk

6. I agree to take part in the above study. ☐

Participant J: Participant debrief

Thankyou for taking part in the study. Please take a screenshot or picture of this page for future reference, as this will not be accessible following exiting the study.

Questions

If you have any further questions or wish to find out more, please get in touch via the email below:

a.l.utting-2017@hull.ac.uk

Support

If you require any additional support, please see the links below:

- Samaritans UK Helpline (24/7) https://www.samaritans.org/how-we-can-help/contact-samaritan/
- MIND (signposting and information service) https://www.mind.org.uk/information-support/helplines/
- FND Hope UK (helpline) https://www.fndhope.org.uk/about-fnd-hope/fnd-hope-uk/uk-telephone-helpline/
- FND Action (UK online support groups) https://www.fndaction.org.uk/facebook-support-groups/

Appendix K: Study advert

UNIVERSITY OF HULL

Do you experience functional/ non-epileptic seizures?

Would you like to help to understand more about their impact?

Yes? Then I need your help for my research

I am looking for people with a diagnosis of **non-epileptic seizures** to take part in my study exploring the psychological impact of the condition (also referred to as functional seizures, NEAD, PNES or dissociative seizures).

I am particularly interested in whether **compassion** plays a role in how people cope with this diagnosis.

Can I take part?

You can take part if:

- You are over 18;
- Do not also have a diagnosis of epilepsy;
- Do not take AEDs (anti-epileptic drugs)
- Are able to complete a survey in English that takes between 35-45 minutes of your time.

If you are interested, please click on this link:
https://hull.onlinesurveys.ac.uk/investigating-the-role-of-compassion-in-the-psychological

Or please feel free to ask any questions by getting in touch at:
a.l.utting-2017@hull.ac.uk

Appendix L: Study survey

p. 1 Information Sheet for Participants (v7 10/11/22)

Edit page
Preview question
Page actions

Add item

INFORMATION SHEET FOR PARTICIPANTS

Title of study: Investigating the Role of Compassion in the Psychological Impact of Non-Epileptic Seizures/ Functional Seizures

We would like to invite you to participate in a research project which looks into the role compassion plays in the mental health impact of living with, and being diagnosed with, functional seizures/ non-epileptic seizures (NES).

This study is a research project forming part of my Clinical Psychology Doctorate research at the University of Hull.

Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask me if there is anything that is not clear or if you would like more information by sending an email to a.l.utting-2017@hull.ac.uk

What is the purpose of the study?

The purpose of this study is to further understand the relationship between functional seizure/ NES severity and its impact on mental health. Research suggests the mental health impact of functional seizure/ NES may be unique, as individuals have increased levels of self-criticism, shame and self-blame, which in turn may further worsen their condition.

Within psychology research, compassion (accepting compassion from others, providing compassion to others and having self-compassion) has shown to decrease these feelings of self-

criticism, self-blame and shame, therefore improving mental health. However, this has not yet been explored within functional seizures/NES.

It is therefore the aim of this study to investigate the role compassion plays on the impact functional seizures/ NES severity has on mental health.

Why have I been invited to take part?

We have looking for adults aged over 18, who have received a diagnosis of non-epileptic seizures/ functional seizures/ non-epileptic attack disorder (NEAD)/ dissociative seizures/ psychogenic non-epileptic seizures.

Am I eligible to take part?

You are eligible to participate in this study if:

- You are an adult over 18 who has received a diagnosis of functional seizures, non-epileptic seizures (NES) or similar
- You are able to read and understand the English language
- You do not have a co-morbid diagnosis of epilepsy
- You are not taking anti-epileptic medication (AEDs)

As important as it is that every person who experiences functional seizures/ NES has the right to have their voice heard, unfortunately all of these factors have the potential to impact the study's results.

What will happen if I take part?

The study has been advertised as a link on various organisation's websites or social media pages such as Facebook, Instagram and Twitter. Once you have read through the following information, you will be presented with a consent form on the following page. Here you will be able to decide whether you would like to participate in the research.

If you decide to take part, you will be presented with:

- A demographic questionnaire (questions about your age, gender and length of time since functional seizure/ NES diagnosis)
- a survey about the severity of your seizures. Here, you will be asked to respond to a series of questions on a maximum scale of 0-5 about the most severe seizure you have experienced in the past four weeks. If you have not experienced a seizure in the past four weeks, respond with your most recent seizure.
- Two compassion questionnaires: one asking about your overall experience with compassion on a scale of 0-10 and another asking about your overall experience on a scale of 0-4.
- A questionnaire asking about your experiences with mental health from the past week on a scale of 0-3.
- A survey asking several questions about your general health, and your health within the past four weeks, on a series of scales.
- A short questionnaire asking about your wellbeing over the past two weeks on a scale of 0-5.

An example from the wellbeing questionnaire is "*I've been feeling optimistic about the future".* The requirements of each questionnaire will be further explained when you commence the study. You will be asked to respond to every question as honestly and accurately as possible. Questionnaires may be over a number of pages, so once all questions on that page have been answered, you will be able to move onto the next page. When you have finished the last question, you will be prompted to click a submit button which will submit your answers and contribute your data to the overall research database to be analysed. There will be a save button so you can save your progress, meaning all questionnaires do not have to responded to in one go. You will be able to withdraw from the study at any point while taking part. Taking part will take no more than 30-40 minutes of your time.

Do I have to take part?

Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in any way. Once you have read the information sheet, please contact us if you have any questions that will help you make a decision about taking part. If you decide to take part, we will ask you to sign a consent form, which will ask you to confirm you have understood this information and had the opportunity to ask any questions. You will be unable to participate in the study until you have consented.

During taking part, you will be able to withdraw from the study at any point, without providing a reason. However, as your information will be completely anonymous, you will be unable to withdraw your data from the research once you have submitted your responses to the surveys.

What are the possible risks of taking part?

The nature of the questions asked in this study has the potential to cause distress as they ask details about your most severe, recent seizure. For some people, this may trigger a seizure. If you are aware this could be a trigger for a seizure, please **do not** take part in this study. You will also be asked potentially distressing questions about your mental health, wellbeing, health and compassion.

Contact details of sources of support will be provided at the end of the study should taking part cause distress. It is suggested you take a picture or a screenshot of the sources of support, as they will not be able to download from the survey website.

What are the possible benefits of taking part?

We are unable to promise any direct benefits of taking part in this study. However, the information you provide will be beneficial in helping us further understand the relationship between functional seizures/ NES and its impact on mental health. This may have further potential benefits on the research into future treatment options for those with functional seizures/ NES.

How will we use information about you?

Your data will be processed in accordance with General Protection Regulation Act, 2016 (GDPR):

- The survey will not ask for any personally identifiable information- all participants' data will remain anonymous throughout the entirety of the research.
- All data gathered will be stored and retained for 10 years as consistent with University of Hull policy.
- Data will be shared with the primary researcher's supervisors, as well as organisations used for recruitment who request a summary of research findings.
- Anonymised data may be used in conference presentations upon the completion of the study

- Data may also be used by future research and so may also be shared anonymously with other researchers.
- Once you have completed the study, your data will be stored safely on the researcher's secure and encrypted laptop meaning the study is also completely confidential.
- The information you provide will help contribute to the results of the study, which will be summarised in a written thesis as part of the researcher's Doctorate in Clinical Psychology. The thesis will be available on the University of Hull's on-line repository https://hydra.hull.ac.uk. The research may also be published in academic journals or presented at conferences.

What are your choices about how your information is used?

While taking part in the study, you can withdraw at any point, and the information you provide will not be saved. However, once you have submitted your responses, your data will not be able to be removed due to the anonymous nature of the research.

Data Protection Statement

The data controller for this project will be the University of Hull. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under GDPR is a 'task in the public interest'.

If you are not happy with the sponsor's response or believe the sponsor processing your data in a way that is not right or lawful, you can complain to the Information Commissioner's Office (ICO) (www.ico.org.uk or 0303 123 1113).

What will happen to the results of the study?

The results of the study will be summarised in a written thesis as part of a Doctorate in Clinical Psychology. The thesis will be available on the University of Hull's on-line repository

https://hydra.hull.ac.uk. The research may also be published in academic journals or presented at conferences and be provided to the organisations who have aided with recruitment. If you want to hear about the results of the study then do contact the researcher, Amy Utting, who will be happy to provide you with a written summary of the research.

How is the project being funded?

This study is being funded by the University of Hull, Cottingham Road, Hull, HU6 7RX.

Who has reviewed this study?

Research studies are reviewed by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and been given a favourable opinion by the Faculty of Health Sciences Ethics Committee, University of Hull.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact the researcher using the following contact details.

Amy Utting

E-mail: a.l.utting-2017@hull.ac.uk

What if I have further questions, or if something goes wrong?

If you wish to make a complaint about the conduct of the study, you can contact the University of Hull using the research supervisor's details below for further advice and information, due to COVID-19 restriction contact via email is preferred:

Dr Philip Molyneux

Clinical Psychology

Aire Building

The University of Hull

Cottingham Road

Hull

HU6 7RX

Tel: +44 (0) 1482 464008
Email address: p.molyneux@hull.ac.uk

Sources of support

- Samaritans UK Helpline (24/7) https://www.samaritans.org/how-we-can-help/contact-samaritan/
- MIND (signposting and information service) https://www.mind.org.uk/information-support/helplines/
- FND Hope UK (helpline) https://www.fndhope.org.uk/about-fnd-hope/fnd-hope-uk/uk-telephone-helpline/
- FND Action (UK online support groups) https://www.fndaction.org.uk/facebook-support-groups/

Thank you for reading this information sheet and for considering taking part in this research.

Edit note
Note actions

Add item

p. 2 Participant Consent From (v5 09/06/22)

1. I confirm that I have read the information sheet dated 09/06/22 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time until the survey is submitted, without giving any reason and without my legal rights being affected.

3. I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers.

4. I give permission for the collection and use of my data to answer the research question in this study.

5. I have read the information sheet and am of the risk that the study may trigger a seizure. I confirm I do not anticipate this risk

1 I agree to take part in the above study

- Yes

p. 3 Eligibility

2 Are you over 18?

- Yes
- No

p. 4 Eligibility

3 Are you able to read and understand the English language?

- Yes
- No

p. 5 Eligibility

4 Do you have a formal diagnosis of non-epileptic seizures (NEAD (non-epileptic attack disorder); PNES (psychogenic non-epileptic seizures; functional seizures; dissociative seizures)?

- Yes
- No

p. 6 Eligibility

5 Do you also have a diagnosis of epilepsy?

Edit question
Question actions

- Yes
- No

Add item
Add item

p. 7 Eligibility

Edit page
Preview question
Page actions

Add item

6 Do you take anti-epileptic drugs (AEDS)?

Edit question
Question actions

- Yes
- No

Add item
Add item

p. 8 Demographics

8 What is your age?

- 18-2
- 26-39
- 40-60

Show all (4)

9 What is your gender?

- Male
- Female
- Non-binary

Show all (4)

10 How many years has it been since you recieved your diagnosis?

11 What is your country of residence?

p. 10 Liverpool Seizure Severity Scale

Liverpool Seizure Severity Scale 2.0

So we can better understand the severity of your seizures, please complete the following questionnaire thinking about the most severe seizure you experienced during the past 4 weeks. (This may be different for each individual, but is based on your most severe seizures over the past 4 weeks.) Your responses are a very important part of this study and will be kept strictly CONFIDENTIAL. No one but the research staff will see your responses. If results of this study are published, only aggregate data will be used; names and any other identifying information will not be reported.

12 Have you experienced a seizure in the past 4 weeks?

- Yes
- No

a If yes, how many seizures have you experienced in the past 4 weeks?

p. 11 Liverpool Seizure Severity Scale- Revised (LSS-3; Scott-Lennox, Bryant-Comstock, Lennox & Barker, 2001)

Please answer each question based on the most severe seizure you have experienced **in the past 4 weeks.**

13 1.

	0-Very Severe	1-Severe	2-Mild	3- Very Mild
I feel that my most severe seizures have mostly been:	Checkbox	Checkbox	Checkbox	Checkbox

14 2.

	1- I blank out for less than a minute	2- I blank out for between 1 and 2 minutes	3- I blank out between 3 and 5 minutes	4- I blank out for more than 5 minutes	0- I never blank out/lose consciousness
Most commonly when I black out/lose consciousness:	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox

Add item
Add item

15 3.

	0- Always	1- Usually	2- Sometimes	3- Never
When I have my most severe seizures, I smack my lips, fidget, or behave in an unusual way:	Checkbox	Checkbox	Checkbox	Checkbox

	0- I feel very confused	1- I feel fairly confused	2- I feel slightly confused	3- I do not feel confused at all
After my most severe seizures, I feel confused	Checkbox	Checkbox	Checkbox	Checkbox

17 5.

	1- Less than 1 minute	2- Between 1 and 5 minutes	3- Between 6 minutes and 1 hour	4- More than 2 hours	0- I never feel confused
After my most severe seizures my confusion lasts for:	Check box	Check box	Check box	Check box	Check box

18 6.

	0- Always	1- Usually	2- Sometimes	3- Never
When I have my most severe seizures, I fall to the ground	Checkbox	Checkbox	Checkbox	Checkbox

19 7.

	0-Always	1-Usually	2- Sometimes	3-Never
After my most severe seizures, I have a headache:	Checkbox	Checkbox	Checkbox	Checkbox

20 8.

	0- Always	1- Usually	2- Sometimes	3- Never

After my most severe seizures, I feel sleepy:	Checkbox	Checkbox	Checkbox	Checkbox
21	9.			
	0-Always	1-Usually	2-Sometimes	3-Never
After my most severe seizures, I find that I have wet myself:	Checkbox	Checkbox	Checkbox	Checkbox
22	10.			
	0-Always	1-Usually	2-Sometimes	3-Never
After my most severe seizures, I find that I have bitten my tongue:	Checkbox	Checkbox	Checkbox	Checkbox
23	11.			
	0-Always	1-Usually	2-Sometimes	3-Never
After my most severe seizures, I find that I have injured myself (other than biting my tongue):	Checkbox	Checkbox	Checkbox	Checkbox
24	12.			

	0-Less than 1 minute	1-Between 1 and 5 minutes	2-Between 6 minutes and 1 hour	3- 1-2 hours	4-More than 2 hours

After my most severe seizures, I can usually return to what I am doing in:	Check box	Check box	Check box	Check box	Check box

p. 12 The Compassionate Engagement and Action Scales

Self-compassion

When things go wrong for us and we become distressed by setbacks, failures, disappointments or losses, we may cope with these in different ways. We are interested in the degree to which people can **be compassionate with themselves**. We define compassion as "a sensitivity to suffering in self and others with a commitment to try to alleviate and prevent it." This means there are two aspects to compassion. The *first* is the ability to be motivated to engage with things/feelings that are difficult as opposed to trying to avoid or supress them.
The *second* aspect of compassion is the ability to focus on what is helpful to us. Just like a doctor with his/her patient. The first is to be motivated and able to pay attention to the pain and (learn how to) make sense of it. The second is to be able to take the action that will be helpful. Below is a series of questions that ask you about these two aspects of compassion. Therefore read each statement carefully and think about how it applies to you if you become distressed.

Please rate the items using the following rating scale:

Never 1 2 3 4 5 6 7 8 9 10 **Always**

Section 1 – These are questions that ask you about how motivated you are, and able to engage with distress when you experience it. So:

25 When I am distressed or upset by things...

	ever-1									lways-10
.I am motivated to engage and work	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box

with my distress when it arises.										
.I notice, and am sensitive to my distressed feelings when they arise in me.	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box
. I avoid thinking about my distress and try to distract myself	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box

and put it out of my mind										
. I am emotionally moved by my distressed feelings or situations.	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box
. I tolerate the various feelings that are part of my distress	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box
. I reflect on and	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box

make sense of my feelings of distress										
. I do not tolerate being distressed	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box
. I am accepting, non-critical and non-judgemental of my feelings of my distress	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box

Section 2- These questions relate to how you actively cope in compassionate ways with emotions, thoughts and situations that distress you. So:

26 When I'm distressed or upset by things...

	ever-1									lways-10
. I direct my attention to what is likely to be helpful to me	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box
. I think about and come up with helpful ways to cope with my distress	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box
. I don't know how to help myself	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box

. I take the actions and do the things that will be helpful to me	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box
. I create inner feelings of support, helpfulness and encouragement	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box

Compassion to others

When things go wrong for other people and they become distressed by setbacks, failures, disappointments or losses, we may cope with their distress in different ways. We are interested in the degree to which people can be **compassionate to others**. We define compassion as "a sensitivity to suffering in self and others with a commitment to try to alleviate and prevent it." This means there are two aspects to compassion. The *first* is the ability to be motivated to engage with things/feelings that are difficult as opposed to trying to avoid or supress them.
The *second* aspect of compassion is the ability to focus on what is helpful. Just like a doctor with his/her patient. The first is to be motivated and able to pay attention to the pain and (learn how to) make sense of it. The second is to be able to take the action that will be helpful. Below is a series of questions that ask you about these two aspects of compassion. Therefore read each statement carefully and think about how it applies to you when **people in your life** become distressed.

Please rate the items using the following rating scale:

Never 1 2 3 4 5 6 7 8 9 10 **Always**

Section 1 – These are questions that ask you about how motivated you are, and able to engage with other people's distress when they are experiencing it. So:

27 When others are distressed or upset by things...

	ever-1									lways-10
. I am motivated to engage and work with other people's distress when it arises	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box
. I notice and am sensitive to distress in others when it	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box

aris es										
. I avo id thi nki ng abo ut oth er peo ple s' dist res s, try to dist ract my self and put it out of my min d	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box
. I am em otio nall y mo ved by exp res sio ns of dist res s in oth ers	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box

.I tolerate the various feelings that are part of other people's distress	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box
. I reflect on and make sense of other people's distress	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box
. I do not tolerate other people's	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box

distress										
. I am accepting, non-critical and non-judgemental of other people's distress	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box

Section 2 – These questions relate to how you actively respond in compassionate ways when other people are distressed. So:

28 When others are distressed or upset by things...

	ever-1								lways-10
. I direct attention to what is likely to be helpful to	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box

others										
. I think about and come up with helpful ways for them to cope with their distress	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box
. I don't know how to help other people when they are distressed	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box
. I take the actions and do the things	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box

that will be helpful to others										
. I express feelings of support, helpfulness and encouragement to others	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box	heck box

p. 13 Fears of Compassion Scale

Different people have different views of compassion and kindness. While some people believe that it is important to show compassion and kindness in all situations and contexts, others believe we should be more cautious and can worry about showing it too much to ourselves and to others. We are interested in your thoughts and beliefs in regard to kindness and compassion in responding to the expression of compassion from others.

Below are a series of statements that we would like you to think carefully about and then circle the number that best describes how each statement fits you.

SCALE

Please use this scale to rate the extent that you agree with each statement

Don't agree at all 0 1 2 3 4 Completely agree

29 Responding to the expression of compassion from others

	Don't agree at all- 0	1	Some what agree- 2	3	Compl etely agree- 4

1. Wanting others to be kind to oneself is a weakness	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox
2. I fear that when I need people to be kind and understanding they won't be	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox
3. I'm fearful of becoming dependent on the care from others because they might not always be available or willing to give it	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox
4. I often wonder whether displays of warmth and kindness from others are genuine	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox
5. Feelings of kindness from others are somehow frightening	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox
6. When people are	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox

kind and compassionate toward me I feel anxious or embarrassed					
7. If people are friendly and kind I worry they will find out something bad about me that will change their mind	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox
8. I worry that people are only kind and compassionate if they want something from me	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox
9. When people are kind and compassionate towards me I feel empty and sad	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox
10. If people are kind I feel they are getting too close	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox
11. Even though other people are	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox

kind to me, I have rarely felt warmth from my relationships with othes					
12. I try to keep my distance from others even if I know they are kind	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox
13. If I think someone is being kind and caring towards me, I 'put up a barrier'	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox

p. 14 DASS-21

30 Please read each statement and circle a number 0,1,2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

	0- Did not apply to me at all	1- Applied to me some degree, or some of the time	2- Applied to me a considerable degree or a good part of the time	3- Applied to me very much or most of the time
1. I found it hard to wind down	Checkbox	Checkbox	Checkbox	Checkbox
2. I was aware of dryness in my mouth	Checkbox	Checkbox	Checkbox	Checkbox
3. I couldn't seem to experience any positive feeling at all	Checkbox	Checkbox	Checkbox	Checkbox

4. I experienced breathing difficulty (e.g.- excessively rapid breathing, breathlessness in the absence of physical exertion)	Checkbox	Checkbox	Checkbox	Checkbox
5. I found it difficult to work up the initiative to do things	Checkbox	Checkbox	Checkbox	Checkbox
6. I tended to over-react to situations	Checkbox	Checkbox	Checkbox	Checkbox
7. I experienced trembling (e.g.- in the hands)	Checkbox	Checkbox	Checkbox	Checkbox
8. I felt that I was using a lot of nervous energy	Checkbox	Checkbox	Checkbox	Checkbox
9. I was worried about situations in which I might panic and make a fool of myself	Checkbox	Checkbox	Checkbox	Checkbox
10. I felt that I had nothing to look forward to	Checkbox	Checkbox	Checkbox	Checkbox
11. I found myself getting agitated	Checkbox	Checkbox	Checkbox	Checkbox
12. I found it	Checkbox	Checkbox	Checkbox	Checkbox

difficult to relax				
13. I felt down-hearted and blue	Checkbox	Checkbox	Checkbox	Checkbox
14. I was intolerant of anything that kept me from getting on with what I was doing	Checkbox	Checkbox	Checkbox	Checkbox
15. I felt I was close to panic	Checkbox	Checkbox	Checkbox	Checkbox
16. I was unable to become enthusiastic about anything	Checkbox	Checkbox	Checkbox	Checkbox
17. I felt I wasn't much as a person	Checkbox	Checkbox	Checkbox	Checkbox
18. I felt that I was rather touchy	Checkbox	Checkbox	Checkbox	Checkbox
19. I was aware of the action of my heart in the absence of physical exertion (e.g.- sense of the heart rate increase, heart missing a beat)	Checkbox	Checkbox	Checkbox	Checkbox
20. I felt scared without any reason	Checkbox	Checkbox	Checkbox	Checkbox
21. I felt that life was meaningless	Checkbox	Checkbox	Checkbox	Checkbox

Add item
Add item

p. 15 Quality of Life in Epilepsy Inventory (QOLIE-10-P)

PLEASE NOTE:
This questionnaire asks questions about epilepsy, **please answer in the context of your functional seizures/ non-epileptic seizures**
This questionnaire also acts questions on the impact of antiepileptic medication. This study requires you to not be prescribed antiepileptic medication. **For these questions, please respond with the lowest possible score**

Part A

These questions are about how you have been FEELING during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

31 How much of the time during the past 4 weeks...

	1- All of the time	2- Most of the time	3. A good bit of the time	4. Some of the time	5. A little of the time	6. None of the time
1. Did you have a lot of energy?	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox
2. Have you felt downhearted and low?	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox

The following questions ask about problems you may have with certain ACTIVITIES

32 How much of the time during the past 4 weeks your epilepsy or antiepileptic drugs have caused trouble with…

	1. A great deal	2. A lot	3. Somewhat	4. Only a little	5. Not at all
3. Driving (or other	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox

transportation)					

33 Please score the lowest possible score for questions 7 & 8
During the past 4 weeks...

	1. Not at all bothersome	2	3	4	5. Extremely bothersome
4. How much do your work limitations bother you?	Check box	Check box	Check box	Check box	Check box
5. How much do your social limitations bother you?	Check box	Check box	Check box	Check box	Check box
6. How much do your memory difficulties bother you?	Check box	Check box	Check box	Check box	Check box
7. How much do physical effects of antiepileptic drugs bother you?	Check box	Check box	Check box	Check box	Check box
8. How much do psychological effects of antiepileptic drugs bother you?	Check box	Check box	Check box	Check box	Check box

34 How afraid are you of having a seizure during the next 4 weeks?

	1- Very afraid	2- Somewhat afraid	3- Very afraid	4- Not afraid at all
9.	Checkbox	Checkbox	Checkbox	Checkbox

35 10. How has your QUALITY OF LIFE been during the past 4 weeks (that is, how have things been going for you)?

- 1- Very good: could hardly have been better
- 2- Pretty good
- 3- Good & bad about equal

Part B

Reviewing all the questions you have answered in Part A, consider the overall impact of these problems on your quality of life in the past 4 weeks.

Please answer in the context of your non-epileptic seizures

36 11.

	1- Not at all	2- Somewhat	3- Moderately	4- A lot	5- Very much
How much does the state of your epilepsy-related quality of life distress you overall?	Check box	Check box	Check box	Check box	Check box

Part C

Considering ALL the questions you have answered, please indicate the areas related to your epilepsy that are most IMPORTANT to you NOW

37 Number the following topics from '1' to '7' with '1' corresponding to the most important topic and '7' to the least important one. Please use each number only once.

	1	2	3	4	5	6	7
A. Energy	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox

(tiredness)							
B. Emotions (mood)	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox
C. Daily activities (work, driving, social)	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox
D. Mental activity (thinking, concentration, memory)	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox
E. Medication effects (Physical, mental)	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox
F. Worry about fits (impact of fits)	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox
G. Overall quality of life	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox	Checkbox

p. 16 Short Warwick-Edinburgh Mental Wellbeing Scale

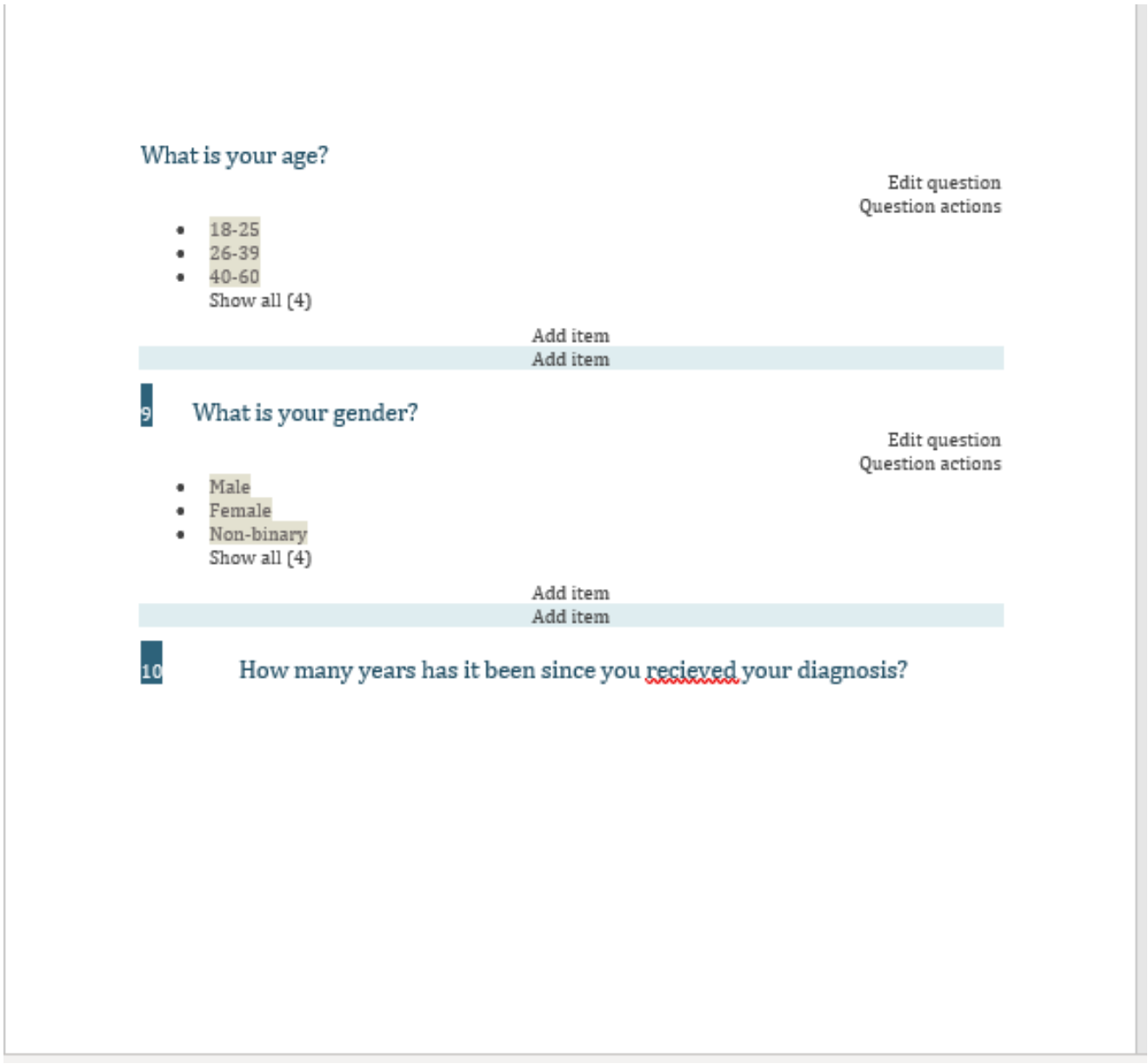
38 Below are some statements about feelings and thoughts. Please tick the box that best describes your experiences of each over the last 2 weeks.

	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	Check box	Check box	Check box	Check box	Check box
I've been feeling useful	Check box	Check box	Check box	Check box	Check box
I've been feeling relaxed	Check box	Check box	Check box	Check box	Check box
I've been dealing with problems well	Check box	Check box	Check box	Check box	Check box
I've been thinking clearly	Check box	Check box	Check box	Check box	Check box
I've been feeling close to other people	Check box	Check box	Check box	Check box	Check box
I've been able to make up my own mind about things	Check box	Check box	Check box	Check box	Check box

p. 17 Final page

Thankyou for taking part in the study. Please take a screenshot or picture of this page for future reference, as this will not be accessible following exiting the study.

Appendix M: Demographic questions



Appendix N: Liverpool Seizure Severity Scale

Please answer each question based on the most severe seizure you have experienced in the past 4 weeks. Circle only one answer for each question.

1. I find that my most severe seizures have mostly been:	Very severe	0	Severe	1	Mild	2	Very Mild	3			
2. Most commonly when I blank out/lose consciousness:	I blank out for less than 1 minute	1	I blank out for between 1 and 2 minutes	2	I blank out for between 3 and 5 minutes	3	I blank out for more than 5 minutes	4	I never blank out/lose consciousness	0	
3. When I have my most severe seizures, I smack my lips, fidget, or behave in an unusual way:	Always	0	Usually	1	Sometimes	2	Never	3			
4. After my most severe seizures:	I feel very confused	0	I feel fairly confused	1	I feel slightly confused	2	I do not feel confused at all	3			
5. After my most severe seizures my confusion lasts for:	Less than 1 minute	1	Between 1 and 5 minutes	2	Between 6 minutes and 1 hour	3	1 to 2 hours	4	More than 2 hours	5	I never feel confused 0
6. When I have my most severe seizures:	I always fall to the ground	0	I usually fall to the ground	1	I sometimes fall to the ground	2	I never fall to the ground	3			
7. After my most severe seizures:	I always have a headache	0	I usually have a headache	1	I sometimes have a headache	2	I never have a headache	3			
8. After my most severe seizures:	I always feel sleepy	0	I usually feel sleepy	1	I sometimes feel sleepy	2	I never feel sleepy	3			
9. After my most severe seizures:	I always find that I have wet myself	0	I usually find that I have wet myself	1	I sometimes find that I have wet myself	2	I never find that I have wet myself	3			
10. After my most severe seizures:	I always find that I have bitten my tongue	0	I usually find that I have bitten my tongue	1	I sometimes find that I have bitten my tongue	2	I never find that I have bitten my tongue	3			
11. After my most severe seizures:	I always find that I have injured myself (other than biting my tongue)	0	I usually find that I have injured myself (other than biting my tongue)	1	I sometimes find that I have injured myself (other than biting my tongue)	2	I never find that I have injured myself (other than biting my tongue)	3			
12. After my most severe seizures I can usually return to what I am doing in:	Less than 1 minute	0	Between 1 and 5 minutes	1	Between 6 minutes and 1 hour	2	1 to 2 hours	3	More than 2 hours	4	

Appendix O: Compassionate Engagement and Action Scale

THE Compassionate Mind FOUNDATION

THE COMPASSIONATE ENGAGEMENT AND ACTION SCALES

Self-compassion

When things go wrong for us and we become distressed by setbacks, failures, disappointments or losses, we may cope with these in different ways. We are interested in the degree to which people can **be compassionate with themselves**. We define compassion as "a sensitivity to suffering in self and others with a commitment to try to alleviate and prevent it." This means there are two aspects to compassion. The *first* is the ability to be motivated to engage with things/feelings that are difficult as opposed to trying to avoid or supress them. The *second* aspect of compassion is the ability to focus on what is helpful to us. Just like a doctor with his/her patient. The first is to be motivated and able to pay attention to the pain and (learn how to) make sense of it. The second is to be able to take the action that will be helpful. Below is a series of questions that ask you about these two aspects of compassion. Therefore read each statement carefully and think about how it applies to you if you become distressed. Please rate the items using the following rating scale:

Never **Always**

1 2 3 4 5 6 7 8 9 10

Section 1 – These are questions that ask you about how motivated you are, and able to engage with distress when you experience it. So:

When I'm distressed or upset by things…

1. I am *motivated* to engage and work with my distress when it arises.

Never **Always**

1 2 3 4 5 6 7 8 9 10

2. I *notice*, and am *sensitive* to my distressed feelings when they arise in me.

Never **Always**

1 2 3 4 5 6 7 8 9 10

(r)3. I avoid thinking about my distress and try to distract myself and put it out of my mind.

Never **Always**

1 2 3 4 5 6 7 8 9 10

4. I am *emotionally moved* by my distressed feelings or situations.

Never **Always**

1 2 3 4 5 6 7 8 9 10

5. I *tolerate* the various feelings that are part of my distress.

Never **Always**

1 2 3 4 5 6 7 8 9 10

THE Compassionate Mind FOUNDATION

6. I *reflect on* and *make sense* of my feelings of distress.

Never **Always**

1 2 3 4 5 6 7 8 9 10

(r)7 I do not tolerate being distressed.

Never **Always**

1 2 3 4 5 6 7 8 9 10

8. I am *accepting, non-critical and non-judgemental* of my feelings of distress.

Never **Always**

1 2 3 4 5 6 7 8 9 10

Section 2 – These questions relate to how you actively cope in compassionate ways with emotions, thoughts and situations that distress you. So:

When I'm distressed or upset by things...

1. I direct my *attention* to what is likely to be helpful to me.

Never **Always**

1 2 3 4 5 6 7 8 9 10

2. I *think* about and come up with helpful ways to cope with my distress.

Never **Always**

1 2 3 4 5 6 7 8 9 10

(r)3. I don't know how to help myself.

Never **Always**

1 2 3 4 5 6 7 8 9 10

4. I take the *actions* and do the things that will be helpful to me.

Never **Always**

1 2 3 4 5 6 7 8 9 10

5. I create inner feelings of *support, helpfulness and encouragement.*

Never **Always**

1 2 3 4 5 6 7 8 9 10

NOTE FOR USERS: REVERSE ITEMS (r) ARE NOT INCLUDED IN THE SCORING

THE Compassionate Mind FOUNDATION

Compassion to others

When things go wrong for other people and they become distressed by setbacks, failures, disappointments or losses, we may cope with their distress in different ways. We are interested in the degree to which people can be **compassionate to others**. We define compassion as "a sensitivity to suffering in self and others with a commitment to try to alleviate and prevent it." This means there are two aspects to compassion. The *first* is the ability to be motivated to engage with things/feelings that are difficult as opposed to trying to avoid or supress them. The *second* aspect of compassion is the ability to focus on what is helpful. Just like a doctor with his/her patient. The first is to be motivated and able to pay attention to the pain and (learn how to) make sense of it. The second is to be able to take the action that will be helpful. Below is a series of questions that ask you about these two aspects of compassion. Therefore read each statement carefully and think about how it applies to you when **people in your life** become distressed. Please rate the items using the following rating scale:

Never **Always**
1 2 3 4 5 6 7 8 9 10

Section 1 – These are questions that ask you about how motivated you are, and able to engage with other people's distress when they are experiencing it. So:

When others are distressed or upset by things…

1. I am *motivated* to engage and work with other peoples' distress when it arises.
Never **Always**
1 2 3 4 5 6 7 8 9 10

2. I *notice* and *am sensitive* to distress in others when it arises.
Never **Always**
1 2 3 4 5 6 7 8 9 10

(r)3. I avoid thinking about other peoples' distress, try to distract myself and put it out of my mind.
Never **Always**
1 2 3 4 5 6 7 8 9 10

4. I am *emotionally moved* by expressions of distress in others.
Never **Always**
1 2 3 4 5 6 7 8 9 10

5. I *tolerate* the various feelings that are part of other people's distress.
Never **Always**
1 2 3 4 5 6 7 8 9 10

THE Compassionate Mind FOUNDATION

6. I *reflect on* and *make sense* of other people's distress.

Never 1 2 3 4 5 6 7 8 9 10 **Always**

(r)7 I do not tolerate other peoples' distress.

Never 1 2 3 4 5 6 7 8 9 10 **Always**

8. I am *accepting, non-critical and non-judgemental* of others people's distress.

Never 1 2 3 4 5 6 7 8 9 10 **Always**

Section 2 – These questions relate to how you actively respond in compassionate ways when other people are distressed. So:

When others are distressed or upset by things....

1. I direct *attention* to what is likely to be helpful to others.

Never 1 2 3 4 5 6 7 8 9 10 **Always**

2. I *think about and come up* with helpful ways for them to cope with their distress.

Never 1 2 3 4 5 6 7 8 9 10 **Always**

(r)3. I don't know how to help other people when they are distressed.

Never 1 2 3 4 5 6 7 8 9 10 **Always**

4. I take the *actions* and *do the things* that will be helpful to others.

Never 1 2 3 4 5 6 7 8 9 10 **Always**

5. I express feelings of *support, helpfulness and encouragement* to others.

Never 1 2 3 4 5 6 7 8 9 10 **Always**

NOTE FOR USERS: REVERSE ITEMS (r) ARE NOT INCLUDED IN THE SCORING

Appendix P: Fears of Compassion Scale

THE Compassionate Mind FOUNDATION

Scale 2: Responding to the expression of compassion from others

1.	Wanting others to be kind to oneself is a weakness	0	1	2	3	4
2.	I fear that when I need people to be kind and understanding they won't be	0	1	2	3	4
3.	I'm fearful of becoming dependent on the care from others because they might not always be available or willing to give it	0	1	2	3	4
4.	I often wonder whether displays of warmth and kindness from others are genuine	0	1	2	3	4
5.	Feelings of kindness from others are somehow frightening	0	1	2	3	4
6.	When people are kind and compassionate towards me I feel anxious or embarrassed	0	1	2	3	4
7.	If people are friendly and kind I worry they will find out something bad about me that will change their mind	0	1	2	3	4
8.	I worry that people are only kind and compassionate if they want something from me	0	1	2	3	4
9.	When people are kind and compassionate towards me I feel empty and sad	0	1	2	3	4
10.	If people are kind I feel they are getting too close	0	1	2	3	4
11.	Even though other people are kind to me, I have rarely felt warmth from my relationships with others	0	1	2	3	4
12.	I try to keep my distance from others even if I know they are kind	0	1	2	3	4
13.	If I think someone is being kind and caring towards me, I 'put up a barrier'	0	1	2	3	4

2

Appendix Q: Depression, Anxiety and Stress Scale

DASS21

Name: Date:

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you **over the past week**. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 Did not apply to me at all
1 Applied to me to some degree, or some of the time
2 Applied to me to a considerable degree or a good part of time
3 Applied to me very much or most of the time

1 (s)	I found it hard to wind down	0	1	2	3
2 (a)	I was aware of dryness of my mouth	0	1	2	3
3 (d)	I couldn't seem to experience any positive feeling at all	0	1	2	3
4 (a)	I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5 (d)	I found it difficult to work up the initiative to do things	0	1	2	3
6 (s)	I tended to over-react to situations	0	1	2	3
7 (a)	I experienced trembling (e.g. in the hands)	0	1	2	3
8 (s)	I felt that I was using a lot of nervous energy	0	1	2	3
9 (a)	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10 (d)	I felt that I had nothing to look forward to	0	1	2	3
11 (s)	I found myself getting agitated	0	1	2	3
12 (s)	I found it difficult to relax	0	1	2	3
13 (d)	I felt down-hearted and blue	0	1	2	3
14 (s)	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15 (a)	I felt I was close to panic	0	1	2	3
16 (d)	I was unable to become enthusiastic about anything	0	1	2	3
17 (d)	I felt I wasn't worth much as a person	0	1	2	3
18 (s)	I felt that I was rather touchy	0	1	2	3
19 (a)	I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat)	0	1	2	3
20 (a)	I felt scared without any good reason	0	1	2	3
21 (d)	I felt that life was meaningless	0	1	2	3

Appendix R: The Short Warwick-Edinburgh Mental Well-being Scale

Removed for digital archiving.

Appendix S: Quality of Life in Epilepsy Inventory

The following questions ask about problems you may have with certain ACTIVITIES.

How much of the time during the past 4 weeks your epilepsy or antiepileptic drugs have caused trouble with...

(Circle one number)

	A great deal	A lot	Somewhat	Only a little	Not at all
3. Driving (or other transportation)	1	2	3	4	5

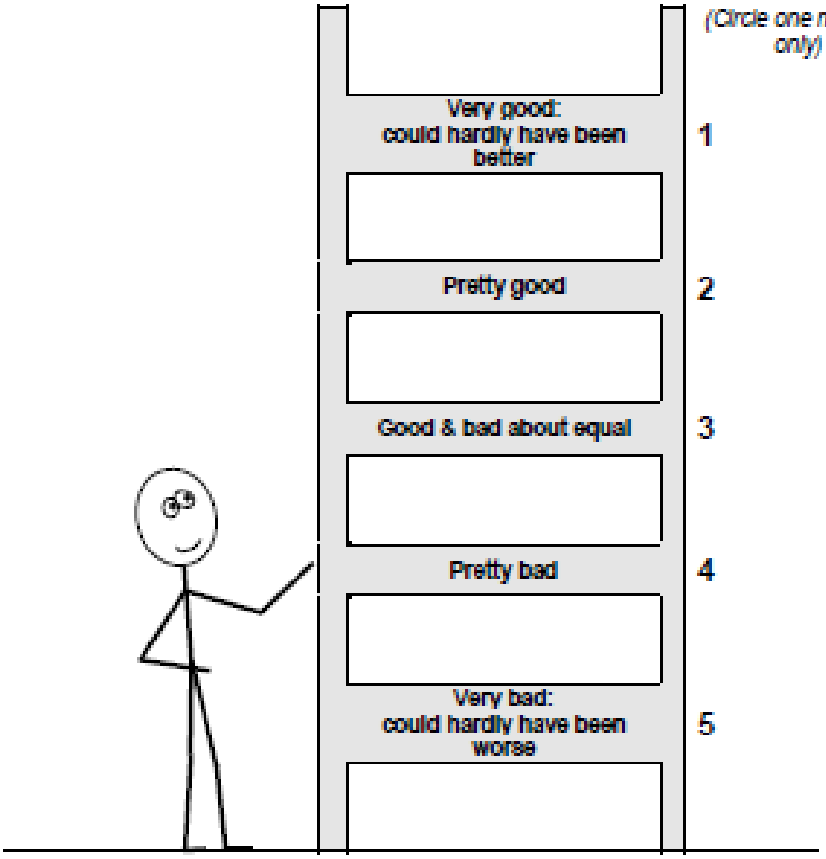
During the past 4 weeks...

	Not at all bothersome				Extremely bothersome
4. How much do your work limitations bother you?	1	2	3	4	5
5. How much do your social limitations bother you?	1	2	3	4	5
6. How much do your memory difficulties bother you?	1	2	3	4	5
7. How much do physical effects of antiepileptic drugs bother you?	1	2	3	4	5
8. How much do psychological effects of antiepileptic drugs bother you?	1	2	3	4	5

	Very afraid	Somewhat afraid	Not very afraid	Not afraid at all
9. How afraid are you of having a seizure during the next 4 weeks?	1	2	3	4

QOLIE-10-P (US English)

10. How has your QUALITY OF LIFE been during the past 4 weeks (that is, how have things been going for you)?



QOLIE-10-P (US English)

Part B.

Reviewing all the questions you have answered in Part A, consider the overall impact of these problems on your quality of life in the past 4 weeks.

(Circle one number)

	Not at all	Somewhat	Moderately	A lot	Very much
11. How much does the state of your epilepsy-related quality of life distress you overall?	1	2	3	4	5

Part C.

Considering ALL the questions you have answered, please indicate the areas related to your epilepsy that are most IMPORTANT to you NOW.

12. *Number the following topics from '1' to '7' with '1' corresponding to the most important topic and '7' to the least important one. Please use each number only once.*

- ___ A. Energy (tiredness)
- ___ B. Emotions (mood)
- ___ C. Daily activities (work, driving, social)
- ___ D. Mental activity (thinking, concentrating, memory)
- ___ E. Medication effects (physical, mental)
- ___ F. Worry about fits (impact of fits)
- ___ G. Overall quality of life

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE ABOUT LIVING WITH EPILEPSY.

Appendix T: Statistical output

Table T.1: Descriptive statistics and skew and kurtosis outputs for each variable

Descriptive Statistics

	N	Range	Minimum	Maximum	Mean	Std. Deviation	Skewness		Kurtosis	
	Statistic	Statistic	Statistic	Statistic	Statistic	Statistic	Statistic	Std. Error	Statistic	Std. Error
8. What is your age?	245	3	1	4	2.09	.808	-.110	.156	-1.352	.310
9. What is your gender?	245	3	1	4	2.00	.434	1.514	.156	9.490	.310
SelfCompassion	245	87.00	13.00	100.00	57.8531	16.48083	-.034	.156	-.384	.310
CompassionToOthers	245	86.00	14.00	100.00	77.7184	16.64326	-1.168	.156	1.615	.310
CompassionFromOthers	245	52.00	.00	52.00	23.6449	12.18742	.062	.156	-.926	.310
Stess	245	42.00	.00	42.00	22.6857	10.78949	-.178	.156	-.735	.310
Anxiety	245	42.00	.00	42.00	21.2245	11.17239	.028	.156	-1.084	.310
Depression	245	42.00	.00	42.00	20.9224	12.73622	.082	.156	-1.185	.310
Wellbeing	245	26.00	7.00	33.00	19.2449	5.25548	-.112	.156	-.290	.310
SeizureSeverity	214	72.50	15.00	87.50	53.0607	15.55623	-.330	.166	-.582	.331
QoL2	245	41.00	13.00	54.00	36.1102	7.19803	-.303	.156	.191	.310
Valid N (listwise)	214									

Model		Collinearity Statistics	
		Tolerance	VIF
1	(Constant)		
	Stess	.383	2.609
	Anxiety	.394	2.538
	Depression	.336	2.980
	Wellbeing	.407	2.458
	QoL2	.621	1.609
	SelfCompassion	.595	1.680
	CompassionToOthers	.726	1.377
	CompassionFromOthers	.575	1.739

Table T.2: Variance Inflation Factor (VIF) and Tolerance Statistics for each variable

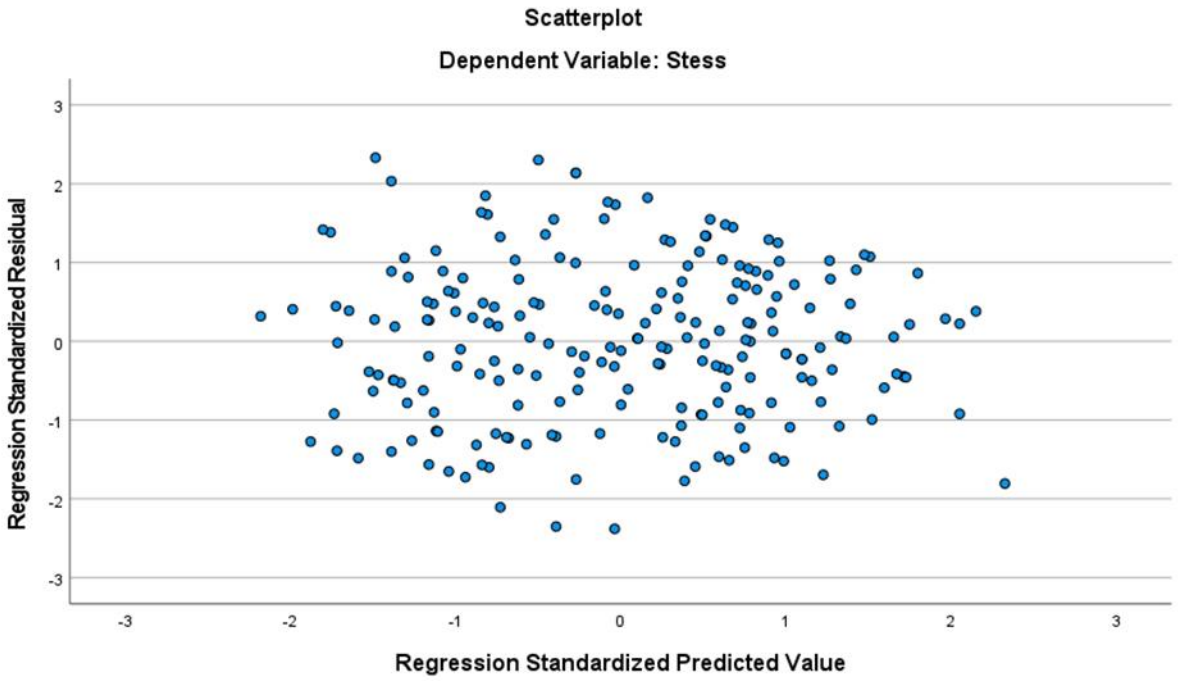


Figure T.1: Scatterplot used to determine Heteroscedasticity for Stress

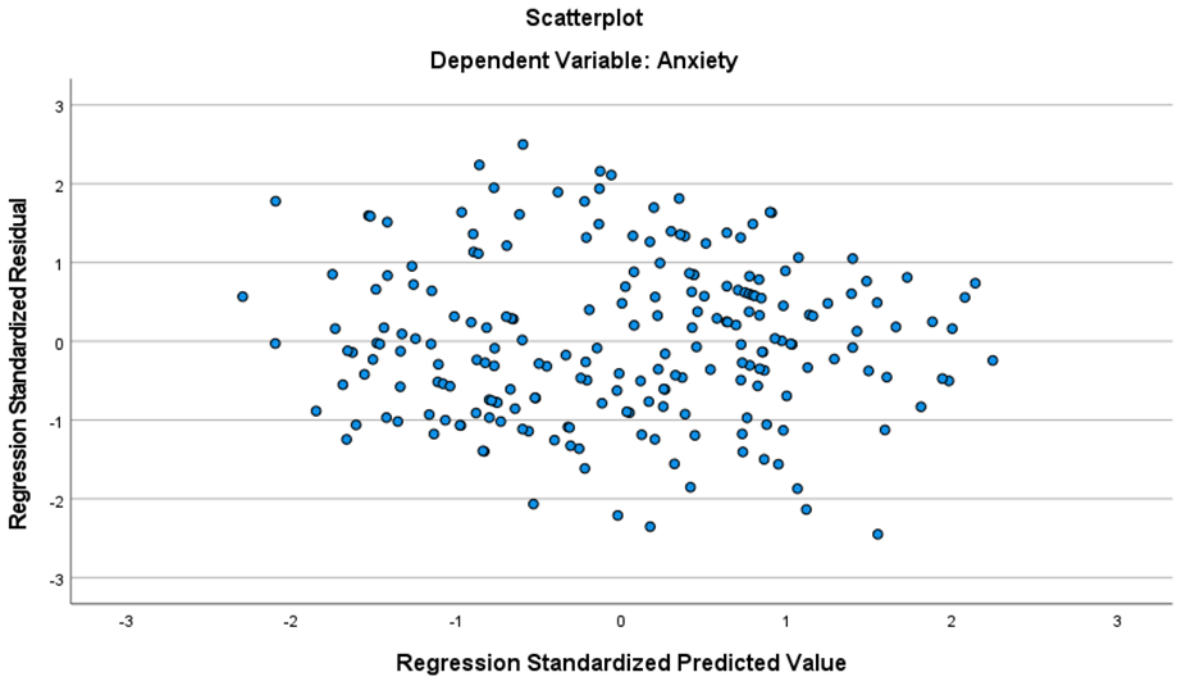


Table T.2: Scatterplot used to determine Heteroscedasticity for Anxiety

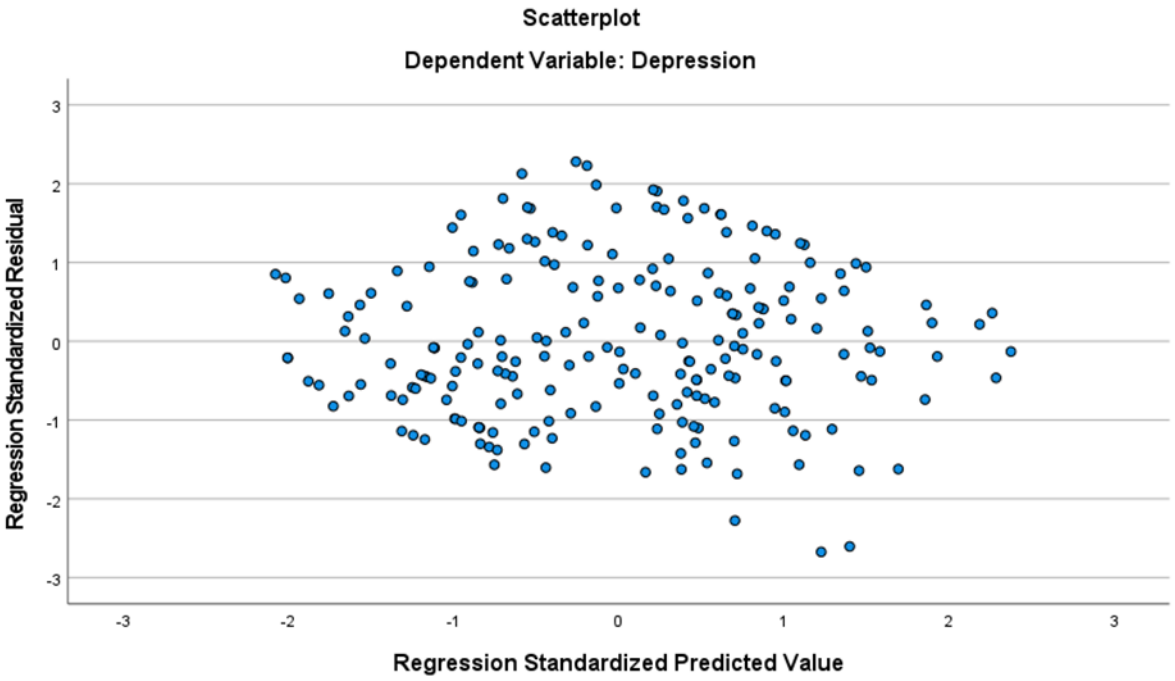


Table T.3: Scatterplot used to determine Heteroscedasticity for Depression

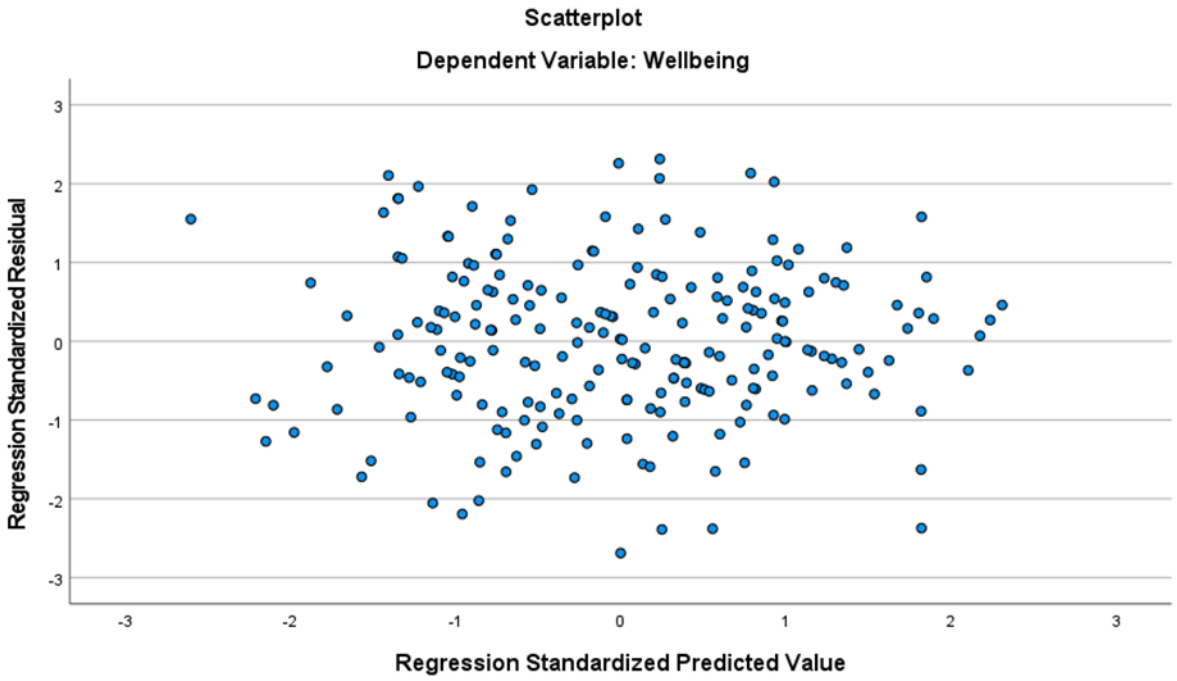


Figure T.4: Scatterplot used to determine Heteroscedasticity for mental wellbeing.

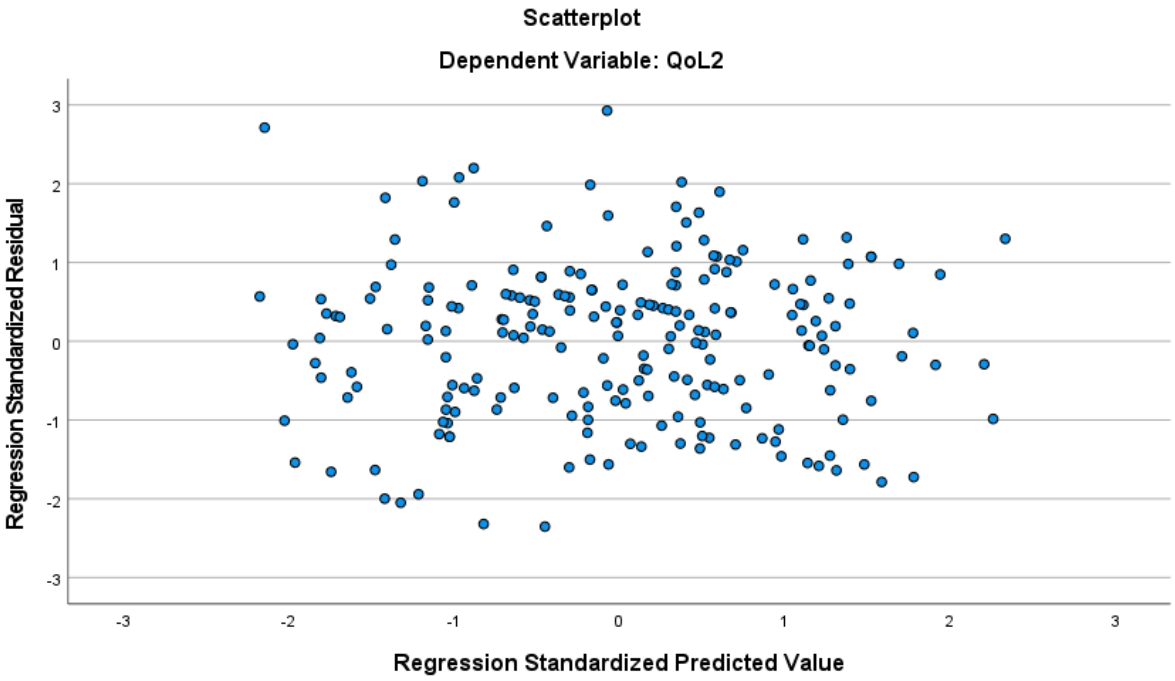


Figure T.5: Scatterplot used to determine Heteroscedasticity for QoL.

Descriptives

			Statistic	Std. Error
YrSDxSqrRt	Mean		1.8903	.06513
	95% Confidence Interval for Mean	Lower Bound	1.7620	
		Upper Bound	2.0186	
	5% Trimmed Mean		1.7738	
	Median		1.7321	
	Variance		1.039	
	Std. Deviation		1.01945	
	Minimum		1.00	
	Maximum		6.40	
	Range		5.40	
	Interquartile Range		1.45	
	Skewness		1.541	.156
	Kurtosis		2.699	.310
YrSDx	Mean		1.0321	.06092
	95% Confidence Interval for Mean	Lower Bound	.9121	
		Upper Bound	1.1521	
	5% Trimmed Mean		.9716	
	Median		1.0986	
	Variance		.909	
	Std. Deviation		.95349	
	Minimum		.00	
	Maximum		3.71	
	Range		3.71	
	Interquartile Range		1.79	
	Skewness		.519	.156
	Kurtosis		-.655	.310

Table T.3: Descriptive statistics and skewness and kurtosis for log and square root transformed variable

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	1777.164	3	592.388	5.467	.001[b]
	Residual	22756.537	210	108.364		
	Total	24533.701	213			
2	Regression	8923.481	7	1274.783	16.823	<.001[c]
	Residual	15610.220	206	75.778		
	Total	24533.701	213			
3	Regression	9239.636	10	923.964	12.264	<.001[d]
	Residual	15294.065	203	75.340		
	Total	24533.701	213			

a. Dependent Variable: Stess

b. Predictors: (Constant), YrSDx, 9. What is your gender?, 8. What is your age?

c. Predictors: (Constant), YrSDx, 9. What is your gender?, 8. What is your age?, SelfCompassion, SeizureSeverity, CompassionFromOthers, CompassionToOthers

d. Predictors: (Constant), YrSDx, 9. What is your gender?, 8. What is your age?, SelfCompassion, SeizureSeverity, CompassionFromOthers, CompassionToOthers, CFOxSS, SCxSS, C2OxSS

Table T.4: Analysis of Variance used to measure the fit of the model for stress

Bootstrap for Coefficients

Model		B	Bootstrap[a] Bias	Std. Error	Sig. (2-tailed)	95% Confidence Interval Lower	Upper
1	(Constant)	22.583	-.060	3.955	<.001	14.178	30.01
	8. What is your age?	-2.812	-.040	.962	.008	-4.850	-1.01
	9. What is your gender?	3.232	.047	1.346	.013	.908	6.13
	YrSDx	-.189	.052	.795	.813	-1.660	1.45
2	(Constant)	7.810	-.021	5.202	.130	-2.444	19.31
	8. What is your age?	-.691	-.039	.848	.401	-2.468	.95
	9. What is your gender?	1.679	.061	1.330	.201	-.726	4.33
	YrSDx	-.778	.051	.729	.287	-2.143	.81
	SelfCompassion	-.039	.001	.046	.402	-.125	.06
	CompassionToOthers	.025	-.001	.043	.559	-.061	.10
	CompassionFromOthers	.469	7.495E-5	.054	<.001	.357	.57
	SeizureSeverity	.059	-.001	.041	.162	-.021	.14
3	(Constant)	8.458	-1.132	12.025	.448	-16.092	29.98
	8. What is your age?	-.661	-.055	.865	.424	-2.476	.99
	9. What is your gender?	1.458	.108	1.417	.302	-1.013	4.48
	YrSDx	-.741	.055	.721	.308	-2.029	.84
	SelfCompassion	.181	-.015	.172	.263	-.213	.48
	CompassionToOthers	-.092	.026	.156	.510	-.354	.26
	CompassionFromOthers	.291	-.002	.186	.110	-.048	.66
	SeizureSeverity	.058	.017	.211	.773	-.325	.49
	SCxSS	-.004	.000	.003	.191	-.010	.00
	C2OxSS	.002	-.001	.003	.427	-.004	.00
	CFOxSS	.003	9.849E-5	.004	.360	-.004	.01

a. Unless otherwise noted, bootstrap results are based on 1000 bootstrap samples

Table T.5: Bootstrap coefficients for stress linear regression

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	1452.711	3	484.237	4.288	.006[b]
	Residual	23714.467	210	112.926		
	Total	25167.178	213			
2	Regression	8907.394	7	1272.485	16.121	<.001[c]
	Residual	16259.783	206	78.931		
	Total	25167.178	213			
3	Regression	9169.338	10	916.934	11.635	<.001[d]
	Residual	15997.840	203	78.807		
	Total	25167.178	213			

a. Dependent Variable: Anxiety

b. Predictors: (Constant), YrSDx, 9. What is your gender?, 8. What is your age?

c. Predictors: (Constant), YrSDx, 9. What is your gender?, 8. What is your age?, SelfCompassion, SeizureSeverity, CompassionFromOthers, CompassionToOthers

d. Predictors: (Constant), YrSDx, 9. What is your gender?, 8. What is your age?, SelfCompassion, SeizureSeverity, CompassionFromOthers, CompassionToOthers, CFOxSS, SCxSS, C2OxSS

Table T.6: Analysis of Variance used to measure the fit of the model for anxiety

Bootstrap for Coefficients

Model		B	Bootstrap[a] Bias	Std. Error	Sig. (2-tailed)	95% Confidence Interval Lower	Upper
1	(Constant)	25.055	.217	4.361	<.001	16.959	34.313
	8. What is your age?	-3.151	.002	.952	<.001	-5.063	-1.338
	9. What is your gender?	1.330	-.120	1.774	.438	-2.577	4.305
	YrSDx	.531	-.001	.753	.486	-.987	1.949
2	(Constant)	8.490	.224	5.688	.137	-2.316	20.797
	8. What is your age?	-.915	.002	.888	.301	-2.716	.800
	9. What is your gender?	-.338	-.040	1.470	.800	-3.424	2.355
	YrSDx	-.132	-.003	.733	.858	-1.675	1.247
	SelfCompassion	-.102	.000	.047	.028	-.188	-.009
	CompassionToOthers	.073	-.003	.041	.076	-.012	.152
	CompassionFromOthers	.419	.000	.050	<.001	.317	.516
	SeizureSeverity	.115	.001	.045	.012	.032	.200
3	(Constant)	-1.303	-2.520	13.854	.909	-38.000	18.708
	8. What is your age?	-.819	-.027	.898	.361	-2.570	.920
	9. What is your gender?	-.317	.020	1.501	.824	-3.342	2.507
	YrSDx	-.166	.006	.739	.812	-1.685	1.234
	SelfCompassion	.044	-.004	.157	.767	-.282	.357
	CompassionToOthers	.124	.029	.161	.406	-.143	.495
	CompassionFromOthers	.285	.017	.177	.100	-.037	.674
	SeizureSeverity	.303	.045	.237	.155	-.046	.896
	SCxSS	-.003	.000	.003	.329	-.009	.004
	C2OxSS	-.001	-.001	.003	.724	-.008	.004
	CFOxSS	.002	.000	.003	.457	-.005	.009

a. Unless otherwise noted, bootstrap results are based on 1000 bootstrap samples

Table T.7: Bootstrap coefficients for anxiety linear regression

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	1896.152	3	632.051	4.280	.006[b]
	Residual	31011.885	210	147.676		
	Total	32908.037	213			
2	Regression	12692.786	7	1813.255	18.478	<.001[c]
	Residual	20215.251	206	98.132		
	Total	32908.037	213			
3	Regression	12952.419	10	1295.242	13.176	<.001[d]
	Residual	19955.618	203	98.304		
	Total	32908.037	213			

a. Dependent Variable: Depression

b. Predictors: (Constant), YrSDx, 9. What is your gender?, 8. What is your age?

c. Predictors: (Constant), YrSDx, 9. What is your gender?, 8. What is your age?, SelfCompassion, SeizureSeverity, CompassionFromOthers, CompassionToOthers

d. Predictors: (Constant), YrSDx, 9. What is your gender?, 8. What is your age?, SelfCompassion, SeizureSeverity, CompassionFromOthers, CompassionToOthers, CFOxSS, SCxSS, C2OxSS

Table T.8: Analysis of Variance used to measure the fit of the model for depression

Bootstrap for Coefficients

Model		B	Bootstrap[a] Bias	Std. Error	Sig. (2-tailed)	95% Confidence Interval Lower	Upper
1	(Constant)	15.325	-.004	4.932	.002	5.408	25.324
	8. What is your age?	-2.080	.013	1.170	.077	-4.363	.314
	9. What is your gender?	5.243	-.014	1.775	.003	1.357	8.653
	YrSDx	-.216	-.009	.910	.816	-1.959	1.660
2	(Constant)	3.233	-.062	5.733	.572	-8.231	13.923
	8. What is your age?	.309	-.015	.947	.748	-1.565	2.194
	9. What is your gender?	3.197	.068	1.389	.021	.566	6.091
	YrSDx	-.851	.010	.851	.312	-2.458	.897
	SelfCompassion	-.188	.002	.059	.002	-.298	-.062
	CompassionToOthers	.091	-.001	.048	.066	-.003	.191
	CompassionFromOthers	.491	-.001	.065	<.001	.354	.612
	SeizureSeverity	.073	-.002	.052	.160	-.031	.169
3	(Constant)	-7.735	-.919	16.698	.602	-43.664	24.524
	8. What is your age?	.380	-.047	.938	.690	-1.470	2.140
	9. What is your gender?	3.221	.084	1.451	.023	.439	6.190
	YrSDx	-.850	.036	.838	.300	-2.443	.896
	SelfCompassion	.061	-.018	.208	.749	-.405	.389
	CompassionToOthers	.001	.019	.177	.995	-.310	.397
	CompassionFromOthers	.647	.020	.241	.009	.178	1.135
	SeizureSeverity	.297	.011	.294	.254	-.264	.905
	SCxSS	-.005	.000	.004	.167	-.012	.004
	C2OxSS	.002	.000	.003	.544	-.005	.007
	CFOxSS	-.003	.000	.004	.452	-.012	.005

a. Unless otherwise noted, bootstrap results are based on 1000 bootstrap samples

Table T.9: Bootstrap coefficients for depression linear regression

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	137.332	3	45.777	1.784	.151[b]
	Residual	5387.977	210	25.657		
	Total	5525.308	213			
2	Regression	2161.093	7	308.728	18.904	<.001[c]
	Residual	3364.215	206	16.331		
	Total	5525.308	213			
3	Regression	2264.908	10	226.491	14.102	<.001[d]
	Residual	3260.401	203	16.061		
	Total	5525.308	213			

a. Dependent Variable: Wellbeing

b. Predictors: (Constant), YrSDx, 9. What is your gender?, 8. What is your age?

c. Predictors: (Constant), YrSDx, 9. What is your gender?, 8. What is your age?, SelfCompassion, SeizureSeverity, CompassionFromOthers, CompassionToOthers

d. Predictors: (Constant), YrSDx, 9. What is your gender?, 8. What is your age?, SelfCompassion, SeizureSeverity, CompassionFromOthers, CompassionToOthers, CFOxSS, SCxSS, C2OxSS

Table T.10: Analysis of Variance used to measure the fit of the model for mental wellbeing

Bootstrap for Coefficients

Model		B	Bootstrap[a] Bias	Std. Error	Sig. (2-tailed)	95% Confidence Interval Lower	Upper
1	(Constant)	21.371	-.214	2.331	<.001	16.486	25.652
	8. What is your age?	.337	-.003	.442	.448	-.584	1.136
	9. What is your gender?	-1.675	.107	.930	.066	-3.253	.388
	YrSDx	.170	.011	.372	.647	-.536	.906
2	(Constant)	20.825	-.188	2.701	<.001	14.803	26.007
	8. What is your age?	-.526	-.002	.386	.187	-1.300	.231
	9. What is your gender?	-.860	.067	.677	.190	-1.965	.698
	YrSDx	.429	-.001	.336	.210	-.235	1.096
	SelfCompassion	.133	.000	.021	<.001	.090	.172
	CompassionToOthers	-.027	.001	.022	.232	-.070	.016
	CompassionFromOthers	-.159	.000	.030	<.001	-.216	-.102
	SeizureSeverity	-.024	.001	.021	.261	-.065	.016
3	(Constant)	23.230	1.033	6.393	<.001	13.426	38.860
	8. What is your age?	-.553	-.002	.390	.168	-1.341	.201
	9. What is your gender?	-.772	.052	.677	.228	-1.887	.735
	YrSDx	.409	.005	.329	.224	-.229	1.080
	SelfCompassion	-.029	.002	.067	.639	-.153	.122
	CompassionToOthers	.059	-.014	.070	.409	-.107	.167
	CompassionFromOthers	-.152	-.009	.098	.107	-.371	.016
	SeizureSeverity	-.079	-.019	.117	.453	-.353	.107
	SCxSS	.003	-6.064E-5	.001	.010	.001	.005
	C2OxSS	-.002	.000	.001	.186	-.004	.001
	CFOxSS	-3.751E-5	.000	.002	.978	-.003	.004

a. Unless otherwise noted, bootstrap results are based on 1000 bootstrap samples

Table T.11: Bootstrap coefficients for wellbeing linear regression

ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	290.230	3	96.743	2.136	.097[b]
	Residual	9510.579	210	45.288		
	Total	9800.808	213			
2	Regression	2669.451	7	381.350	11.016	<.001[c]
	Residual	7131.358	206	34.618		
	Total	9800.808	213			
3	Regression	2947.780	10	294.778	8.732	<.001[d]
	Residual	6853.029	203	33.759		
	Total	9800.808	213			

a. Dependent Variable: QoL2

b. Predictors: (Constant), YrSDx, 9. What is your gender?, 8. What is your age?

c. Predictors: (Constant), YrSDx, 9. What is your gender?, 8. What is your age?, SelfCompassion, SeizureSeverity, CompassionFromOthers, CompassionToOthers

d. Predictors: (Constant), YrSDx, 9. What is your gender?, 8. What is your age?, SelfCompassion, SeizureSeverity, CompassionFromOthers, CompassionToOthers, CFOxSS, SCxSS, C2OxSS

Table T.12: Analysis of Variance used to measure the fit of the model for QoL

Bootstrap for Coefficients

Model		B	Bootstrap[a] Bias	Std. Error	Sig. (2-tailed)	95% Confidence Interval Lower	Upper
1	(Constant)	32.707	.178	2.781	<.001	27.628	38.45
	8. What is your age?	.393	.004	.577	.496	-.760	1.54
	9. What is your gender?	2.025	-.118	1.138	.057	-.518	3.91
	YrSDx	-.961	.022	.486	.054	-1.947	.04
2	(Constant)	20.614	.003	3.600	<.001	13.807	27.81
	8. What is your age?	1.544	.023	.512	.003	.546	2.54
	9. What is your gender?	1.115	-.058	.809	.148	-.567	2.53
	YrSDx	-1.314	.010	.465	.008	-2.216	-.37
	SelfCompassion	-.102	.000	.032	.003	-.164	-.03
	CompassionToOthers	.105	-.001	.028	<.001	.048	.15
	CompassionFromOthers	.144	.001	.039	<.001	.070	.21
	SeizureSeverity	.116	.002	.027	<.001	.062	.17
3	(Constant)	40.014	-1.442	8.912	<.001	19.708	54.14
	8. What is your age?	1.410	.017	.513	.006	.437	2.42
	9. What is your gender?	.893	-.035	.845	.285	-.854	2.42
	YrSDx	-1.248	.017	.461	.008	-2.120	-.30
	SelfCompassion	-.266	-.014	.109	.012	-.513	-.09
	CompassionToOthers	.018	.025	.101	.869	-.133	.25
	CompassionFromOthers	.033	.009	.116	.763	-.193	.27
	SeizureSeverity	-.256	.027	.158	.086	-.504	.10
	SCxSS	.003	.000	.002	.103	-6.352E-5	.00
	C2OxSS	.002	.000	.002	.374	-.003	.00
	CFOxSS	.002	.000	.002	.268	-.002	.00

a. Unless otherwise noted, bootstrap results are based on 1000 bootstrap samples

Table T.13: Bootstrap coefficients for QoL linear regression