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Doctoral Thesis

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The Role of Self-compassion in Neurological Conditions

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Megan Hawkes

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Thesis Abstract

This thesis explores the role self-compassion may play within neurological conditions.

Section one includes a scoping review which examines how self-compassion is investigated within neurological conditions, with a particular focus on intervention studies. Five academic databases were searched in November 2022 and 17 papers met all criteria and were included. The interventions utilised could be broadly split into two types, compassion-focused (such as Compassion Focused Therapy) and mindfulness-based (such as Mindfulness Based Stress Reduction). The compassion-focused studies did not always measure self-compassion, which meant that changes in outcomes could not be clearly attributed to changes in self-compassion. Both intervention types targeted changes to well-being and physical health or psychological distress. Findings suggested that developing self-compassion may take time, which has implications both clinically and for research. Suggestions for future research are made, including the methodology and measures used for investigating self-compassion and the neurological conditions examined.

Section two involves an empirical study investigating the role of self-compassion and experiential avoidance in functional seizures. People who experience functional seizures completed an online survey including measures of self-compassion, experiential avoidance, depressive symptoms, seizure severity, seizure frequency and quality-of-life. Correlational and mediation analyses were conducted to examine the relationships between all variables. Correlational relationships were all in expected directions, apart from seizure frequency which did not have a significant relationship with self-compassion. Experiential avoidance significantly mediated the relationship between self-compassion and several outcomes (depressive symptoms, quality-of-life, and seizure severity). These findings suggest the

importance of developing compassion-cultivating interventions for those with functional seizures.

Section three is the critical appraisal, which reflects on the decisions made and any issues which arose during the process of conducting this project.

Declaration

This thesis is the author's own work and was undertaken as part of the Doctorate in Clinical Psychology at the Division for Health Research, Lancaster University. The work has not been submitted for any another academic award.

Name: Megan Hawkes

Signature:

Date: 15/05/2023

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Section 1: Literature Review

How has Self-compassion been Investigated within Intervention Studies in Neurological Conditions? A Scoping Review

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Megan Hawkes

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All correspondence should be sent to:

Megan Hawkes
Doctorate in Clinical Psychology
Health Innovation One
Lancaster University
LA1 4AT
Email: m.hawkes@lancaster.ac.uk

Abstract

Purpose: Within research higher levels of self-compassion have been associated with greater well-being, both within non-clinical populations and within those with long-term health conditions. However, people with neurological conditions have not featured as prominently in this area of research. This scoping review aimed to explore how self-compassion has been investigated in neurological conditions within intervention studies. **Materials and Methods:** The databases PsycINFO, MEDLINE, CINAHL, AMED and Web of Science were searched in November 2022. **Results:** A total of 17 papers met all criteria and were included in the review. The studies could be broadly split into two categories: compassion-related interventions which directly aimed to change self-compassion and mindfulness-related interventions which viewed self-compassion as one possible mechanism of change. Multiple sclerosis was the most investigated condition in mindfulness-related studies, and brain injuries were most frequent in compassion-related interventions. Most studies adopted a pre and post-test design and seven studies were randomised control trials. **Conclusions:** This area of research in neurological conditions is still limited, particularly for conditions such as functional neurological disorders, migraine, or chronic fatigue syndrome, which all featured only once in this review. Furthermore, the research that does exist is often small sample, does not consistently report clear methodology and does not always explicitly measure self-compassion. Compassion-focused interventions have been hugely variable, and the mechanism of change is often unclear. Self-compassion is emerging as a potential change process in mindfulness-based work. The process of developing self-compassion may also take time, which has potential implications for rehabilitation. Ideas for future research and limitations of the included studies are discussed.

Keywords: Self-compassion, Neurological Condition, Neurological Disorder, Mindfulness, Review

Introduction

The World Health Organization suggests that around 1 billion people experience a neurological condition worldwide and that this number is set to rise [1]. Additionally, a study suggested that within one area of the UK, 6 percent of the population examined had experienced a neurological disorder, and the lifetime prevalence rates in this study showed that the most common conditions were (in order); stroke, epilepsy, congenital conditions, Parkinson’s disease, multiple sclerosis, neuropathies and subarachnoid haemorrhage [2]. Furthermore, while stroke potentially has the highest prevalence of neurological conditions in Europe, other conditions also have a higher incidence rate such as brain injuries, multiple sclerosis (MS) and spinal cord injuries [3,4]. Moreover, similar rates are seen in the United States, with recent increases observed in stroke and Alzheimer’s disease [5]. Therefore, neurological conditions affect a substantial proportion of the population, who require, according to their individual physical needs, different levels, and type of support.

However, research consistently suggests that those with a neurological condition are likely to experience mental health difficulties. For example, anxiety and depression are common in many neurological conditions [6–9]. People who have a neurological condition are also likely to report having a lower quality-of-life (QoL) compared to people without a neurological condition [10–13]. Additionally, people with neurological conditions frequently experience shame or stigma surrounding their condition [1,14–16], further impacting their well-being; it is therefore important to explore interventions which may improve psychological well-being.

A psychological construct often associated with well-being is self-compassion [17,18]. Whilst there are many varied definitions of self-compassion, two of the most prominent ones in research are described here for the purposes of giving an overview of the conceptualisation of self-compassion [19,20]. Neff [21] derived her conceptualisation of self-compassion from Buddhism, arguing that self-compassion involves being ‘open to one’s suffering’ without avoidance. Neff also posits that self-compassion includes three main elements; being supportive instead of judgmental towards oneself, understanding that one’s difficulties are part of common humanity and it therefore being important not to isolate oneself from others, and acknowledging one’s suffering without becoming absorbed by this [22]. Each element of self-compassion has ‘polar’ ends (for example, self-kindness at one end and self-criticism at another). Other conceptualisations of self-compassion have also emerged, including that of Gilbert, who defines self-compassion from an evolutionary perspective and describes how self-compassion involves being sensitive to one’s own suffering and being committed to ‘try to alleviate and prevent it’ [23, p.11]. Gilbert [24] suggests that the ‘compassion system’ is neurologically separate from the ‘critical system’, both in terms of his model and the physical areas of the brain activated by self-compassion or self-criticism. Additionally, Gilbert’s definition has a focus on a commitment to action, such as developing wisdom or skills of compassion rather than just engagement in self-compassion [25].

Regardless of theoretical underpinnings, higher levels of self-compassion are typically associated with better psychological and physical health outcomes in clinical [26] and non-clinical [27] populations. For example, a meta-analysis found that higher levels of self-compassion are associated with greater resilience and well-being in both student, therapist and clinical samples [28]. However, the underlying mechanism of this relationship is not always clear. Self-compassion may indirectly affect well-being by influencing another process, such as emotion regulation [29], perceived stress [30], health-promoting behaviour [31], experiential avoidance [32] or coping style [33]. The inverse of this may also be true, with an internal process (such as mindfulness or self-criticism) indirectly affecting well-being through impacting self-compassion [34,35]. Thus, understanding the mechanism behind these statistical associations remains an important area of study.

Self-compassion in physical health conditions has been explored previously in systematic reviews. These reviews generally report that lower self-compassion is associated with increased psychological distress such as anxiety and depression, and reductions in positive health outcomes [36,37]. Reviews on self-compassion interventions in physical health conditions have noted that these interventions lead to some improvement in self-compassion and mental health outcomes [38–40] but the size of effect is uncertain as one reported small effect sizes [39] and another medium to large [40]. Despite these promising findings, these reviews were limited in the neurological conditions examined, instead opting to focus on other physical health conditions such as chronic pain or cancer [37–40]. One review did not include any neurological conditions [37], two reviews included a small amount of neurological conditions such as 2 studies out of the 15 examined [40] or 5 out of the 20 health condition studies explored [38]. However, this review with 5 neurological papers excluded any studies which did not specifically seek to train self-compassion, therefore potentially missing studies in which self-compassion was a secondary measure or changed when targeting another internal process. Another review explored self-compassion interventions in chronic illness groups, but did not include any specific neurological condition study, instead examining studies with mixed chronic illness samples [39].

It is important to consider that people with neurological conditions may face additional or specific difficulties compared to those with physical health conditions. For example, people with neurological conditions can experience various cognitive impairments which impact their QoL [41], alongside ongoing persistent difficulties such as chronic fatigue [42]. Individuals can also experience stigma in relation to their neurological condition, which can be related to the invisibility of some symptoms of their condition [43,44]. Given that people with neurological conditions may face specific challenges, it is important to explore the role of self-compassion with this patient group specifically.

While the growing literature base of self-compassion interventions in mental health and physical health has permitted meta-analyses of effect as indicated above, the literature surrounding interventions involving self-compassion in neurological conditions is at an earlier stage. Nonetheless a small corpus of work now exists and therefore it is timely to summarise and explore this in order to highlight the issues specific to neurological conditions and to guide further research and practice. A scoping review was deemed the best approach to meet this aim. One review exists on the use of third-wave therapies in neurological conditions, which concluded that Compassion Focused Therapy (CFT), Acceptance and Commitment Therapy (ACT) and mindfulness-related therapies were promising in their ability to reduce distress within neurological conditions [45]. However, this review did not explicitly look at the role of self-compassion or internal processes within third-wave interventions; instead, it focused on whether the interventions were effective in reducing unwanted outcomes. Additionally, due to compassion being a growing area of study, there are more recent studies not included in this existing review.

Consequently, this review will focus on the role of self-compassion in interventions to improve wellbeing for people with neurological conditions. Specifically, it will examine how self-compassion has been investigated including the content of interventions, the intended outcomes, the research methodology, characteristics of the samples examined and mechanisms of change. Factors specific to neurological conditions will also be highlighted, including which conditions have been investigated and what adaptations have been trialled.

Method

A scoping review was chosen to enable the researchers to map out the existing research and identify gaps in the literature, which could guide future research. Therefore the aims (mapping research and exploring concepts) of this review were best met using a scoping review methodology [46]. The ability to explore how self-compassion has been investigated using this method could also aid future systematic reviews in the area by clarifying review questions and noting how self-compassion has been conceptualized within this research. Furthermore, an initial search of the literature was carried out, which highlighted heterogeneity in the methodology of the research. This suggested that a broad search strategy and research question could be helpful, which was best met by adopting scoping review methodology [46]. This scoping review followed the methodology outlined by Arksey and O'Malley [47] and guidelines from the Joanna Briggs Institute [48]. The PRISMA-ScR Checklist [49] was also used, which can be seen in Appendix 1-2.

Stage 1: Identifying the research question

Initial searches regarding self-compassion and neurological conditions were made through Google Scholar, with the broad research question of *'how has self-compassion been investigated in neurological conditions?'*. Formal searches were then conducted using search terms which can be seen in Table 1-1. Due to the breadth of literature and key messages from the research that emerged when collating the studies, it was decided that this review would be split into two reviews, one focusing on intervention studies and the other focusing on observational studies such as quantitative correlational studies or qualitative studies. This secondary scoping review on observational studies is currently being written by the same research team. This current paper focuses on intervention studies. There is no online review protocol for this scoping review.

The research question for this review was initially framed as *how has self-compassion been investigated in neurological conditions within intervention studies?* This was then further broken down into the following questions: *which neurological conditions have been studied?, what are the characteristics of the samples investigated?, what interventions have been trialled in this area (including the format and model used)?, what adjustments have been made for neurological conditions?, what methodology has been used in the research?, what outcomes have been targeted?* and *what are the proposed mechanisms of change?.*

Stage 2: Identifying relevant studies

To identify a list of neurological conditions, existing literature reviews on neurological conditions were consulted [45,50,51] as well as the World Health Organization's list of neurological disorders in their 'Neurological Disorders: Public Health Challenges' report [1]. Advice was also taken from a clinical neuropsychologist as well as a specialist librarian.

Two main concepts were searched for: compassion/self-compassion and neurological conditions. The search terms for all databases can be seen in Table 1-1. Search terms consisted of free text and subject headings where the database allowed for this. The free text terms were set to search the titles and abstracts of papers. Boolean operators were used, for example the use of 'AND' to combine the self-compassion and neurological condition concepts, and the use of 'OR' for the list of neurological conditions.

The databases searched were: PsycINFO, MEDLINE, CINAHL, AMED and Web of Science. These databases were selected to cover a range of areas relevant to research on neurological conditions and self-compassion. The final searches were run on 15/11/2022.

Stage 3: Study selection

Papers were included if they were in English or had an English translation by the original authors readily available. There were no exclusion criteria for participant age, location, or year of study publication. Neurological conditions were included regardless of whether they were degenerative, ongoing, or short-term. For the purposes of this review neurological conditions were defined as damage to the brain, nerves or spine due to an injury or illness, which is a definition given by The Neurological Alliance [52]. The decision was made to include functional neurological conditions, for example, functional movement disorders and functional seizures. Conditions were excluded if the main symptom was pain or they fell under the umbrella of a chronic pain condition, such as complex regional pain syndrome, due to there being an existing review on self-compassion in pain [53].

The compassion explored in the papers had to be concerning compassion towards self, not towards others or from others. Papers on compassion fatigue were excluded as this refers to a different concept [54,55]. Papers on the ‘compassionate use’ of medication or self-compassion in carers of those with neurological conditions were also excluded. Papers were included if they contained an intervention where the aim was to utilise self-compassion to improve outcomes or the aim was to improve self-compassion or self-compassion was measured as a potential change mechanism.

Only peer-reviewed published papers were included, ensuring a basic level of quality, a deviation from the approach proposed by Arksey and O’Malley [47]. This led to the exclusion of two book chapters [56,57] and one poster presentation [58]. It was helpful to have some structure and record of the process of study selection and therefore the PRISMA diagram [59], figure 1-1, was used. This specific review will focus on the 17 intervention papers retrieved.

[Insert Figure 1-1 here]

All studies were read by the researcher and hand filtered. Rayyan, an online systematic review management tool, was used to track decision-making. Where the researcher was unsure of whether to include or exclude a paper, this was discussed with a supervisor and a collaborative decision was reached.

Stage 4: Charting the data

In order to extract data from the papers, a bespoke data extraction table was created and used which can be seen in Table 1-2. This was then tested against two key papers to make sure it worked well.

Stage 5: Collating, summarizing and reporting the results

While writing the results, the researcher continued to follow the scoping review guidelines [47,48], firstly presenting the quantity of each type of study and how frequently each condition had been studied, followed by a narrative account of the findings. While quality appraisal tools are not routinely used in scoping reviews [60], a tool was used in the present review to describe the methodology used and potential for risk of bias. The tool used was taken from the ‘Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields’ [61] and was chosen due to the checklist’s ability to assess a range of study designs. This checklist can be seen in Table 1-3.

Results

The search across all the databases yielded 2757 results. De-duplication was carried out using referencing software tools (Mendeley) and by hand. There were 826 duplicates and 5 papers not available in English, which were removed. The remaining papers were then first screened by title and abstract; 1872 papers were removed, and 54 papers were carried forward into the next screening stage. In the second screening stage, the full-text versions of the 54 papers were read by the researcher. After this process, 37 papers remained, 17 of which were intervention studies and were included in this review. The studies included in the review were published between 2011- 2022.

Which neurological conditions have been studied?

The most common conditions researched in these papers were MS (*n*=6), followed by brain injuries (*n*=5), dementia (*n*=3), migraine (*n*=1), chronic fatigue syndrome (CFS) (*n*=1) and motor functional neurological disorder (*n*=1). The studies examining people with MS used a mindfulness-based intervention, measuring self-compassion as a mechanism within this intervention. On the other hand, the brain injury studies used varied compassion-focused interventions. The motor functional neurological disorder study was a compassion-focused intervention, and the chronic fatigue syndrome study was a mindfulness-related intervention. People with dementia were investigated across both compassion-focused and mindfulness-related interventions.

What are the characteristics of the samples investigated?

The studies were mainly conducted in the United Kingdom (*n* = 10) but also included Netherlands (*n* = 2), Australia (*n* = 2), Iran (*n* = 2) and Switzerland (*n* = 1). The majority of the studies took place in Western countries, and so the studies may not be generalisable to other countries or cultures as concepts such as self-compassion may differ worldwide [62,63].

In terms of participants, the sample size ranged between 1-126 and the reported average participants' age ranged between 20 and 81. Outside of the case studies, the gender proportions ranged from 8.7% male which was a MS study [64] to 83% male, a head injury study [65].

In terms of recruitment, five studies took place within neurorehabilitation programs or inpatient services. Ten studies recruited participants from condition-specific clinics or NHS services, seven recruited through neurological condition charities and support groups, one recruited from non-charity online channels such as social media, one recruited through ‘local advertisements’ such as flyers and one recruited from a university ‘study day’ specifically for people with MS. Studies in this review commonly recruited participants from clinics or through condition-specific support groups or charities. It is possible that this led to some similarities within samples, for example, participants may be more ‘support-seeking’ in nature if they attend these clinics or groups and this ‘support-seeking’ could be related to their level of self-compassion, psychological well-being, or physical health. This has been seen in non-clinical research, with high levels of care-seeking predicting high levels of self-compassion [66].

Diagnosis confirmation varied between studies, including using; current neurorehabilitation clients (5 papers), self-report (3 papers), condition-specific questionnaires (2 papers), neuropsychological or cognitive assessment (3 papers), magnetic resonance imaging (1 paper) and diagnosis from condition-specific NHS service (2 papers). Five studies did not include information regarding diagnosis confirmation in their paper. However, as some studies recruited from inpatient and outpatient programs, it is probable that participants had to have a clinician-given diagnosis to access the service.

What interventions have been trialled?

The search was for any intervention which had measured self-compassion or used self-compassion techniques. The papers retrieved, could be broadly split into two groups, with eight studies using a compassion-focused intervention, and seven studies using a mindfulness-based intervention, yet measuring self-compassion as part of their outcomes. However, some studies noted using elements of both approaches, such as one paper which used a ‘mindfulness-compassion intervention’ [67] or another which compared CFT to ACT [68]. Information on intervention format and location of the delivery of the intervention can be seen in Table 1-2. All mindfulness-based interventions were group interventions, whereas most compassion-focused interventions were delivered on an individual basis (6/8 studies). Only one mindfulness study noted that the intervention was delivered remotely, with the other papers in this review reporting the delivery of the intervention as in person or did not specify the location.

Nine studies reported using CFT or an element of CFT, however the length and format of the CFT sessions differed between studies. Ashworth et al. [69] used 18 sessions of 1:1 CFT after an initial six sessions of Cognitive Behavioural Therapy (CBT) in their TBI study. Another brain injury study included CFT as part of their ‘mood group’ intervention alongside the minimum 18-session 1:1 CFT intervention participants were receiving [70]. A group CFT intervention for people with dementia with six 2-hour sessions reported that the intervention was led by the needs of the participants instead of using a manualised approach [71]. Another individual intervention for people with dementia consisted of 10 sessions [72]. There was one case-study using CFT over 12-weeks in 1-hour long sessions with a person with Motor Functional Neurological Disorder [73]. However, some papers were not clear on how the CFT intervention was carried out or how long this was for [74]. One study compared the use of CFT and ACT for MS, but did not give details on either intervention [68]. There were two compassion-focused imagery for brain injury studies, one using a 30-minute video [75] and one using a 50-minute video [65].

Self-compassion was investigated as a change process in 8 papers on mindfulness-related interventions such as Mindfulness Based Stress Reduction (MBSR) and mindfulness-based cognitive therapy (MBCT). Similarly, to the CFT interventions, mindfulness studies varied in length and format. Two studies with MS samples used 8-session MBSR [76,77]. Three studies stated they adapted 8-week MBSR or MBCT for a specific condition such as dementia [78], MS [79] and CFS [80]. Two MS studies also took this approach but in the format of 5 two hour sessions [64,81]. One study did not give details on the adaptations or content of the intervention [79] and another adapted the intervention to a 5-week intervention for MS, but gave details of the content of the intervention [64]. One study took aspects of MBSR, MBCT and 'Mindfulness-Based Compassionate Living', alongside relational and attachment elements of mindfulness to create a manualised intervention for their ABI sample [67].

What adjustments have been made for neurological conditions?

As well as adjustments being made to the format and delivery of the interventions, some studies detailed the adaptations they made to the intervention for the specific condition of the participants. For example, some studies shortened the length of each intervention session or incorporated breaks due to attentional or fatigue difficulties; this was seen in brain injury, MS and CFS studies [64,67,70,80–82]. Some dementia and brain injury studies used repetition, slower pacing, written summaries and visual information to support information processing and aid memory [67,70–72,78,82]. Two dementia studies used the CFT model to aid a person's understanding of their dementia, either describing dementia as part of the 'threat' system in the three-systems model [71] or viewing dementia as part of a 'trickier brain' in the evolutionary model [72]. Two MS studies introduced the body scan exercise at a later point than normally seen in MBSR, due to the physical discomfort that can arise from this in MS [64,81]. Additionally, some studies removed or modified mindful movement exercises due to potential physical limitations of participants' conditions (CFS, dementia and MS) [64,78,80,81]. Some mindfulness techniques were used within compassion-focused interventions, as seen in a dementia and a brain injury study [71,82], sometimes to aid attentional difficulties [82].

What methodology has been used?

The methodology used by the studies varied, with most papers being quantitative (*n* = 11) and some including qualitative elements for a mixed-method approach (*n* = 6).

Four RCTs used compassion-focused interventions with people with migraine [74], brain injury [65,75] and MS [68]. Three RCTs used mindfulness-related interventions with people with MS [79], CFS [80] and brain injury [67]. One RCT explored the use of animal assistance in a combined compassion and mindfulness intervention [67].

The majority of the intervention studies in this review (10 studies) adopted a single pre-post design [64,70–73,76–78,81,82]. These pre-post design studies investigated people with brain injuries (2 studies), dementia (3 studies), multiple sclerosis (4 studies) and functional movement disorder (1 study). Six of these studies used compassion-focused interventions.

Six intervention studies used a mixed-methods approach, analysing qualitative data regarding the feasibility and acceptance of the intervention (as well as general participant feedback) in addition to quantitative data [64,70,72,78,79,81]. The outcome measures used in each study can be found in Table 1-2.

The studies varied widely in terms of quality, as can be seen in Table 1-3. Understandably, some of the highest quality scores were seen in the RCT designs. However, one RCT comparing ACT and CFT in MS [68] scored relatively low due to poor descriptions of the methodology and unclear randomisation method. Although conclusions are more limited than for RCTs, interestingly, the pre-post design studies scored relatively well with the exception of one compassion-focused intervention for people with dementia [72], due unclear descriptions of the methodology and inadequate sample size. A small, and inappropriate, sample size was observed for five papers in this review, four of which were compassion-focused interventions [65,70,72,74,78].

What outcomes were targeted in the interventions?

The papers generally reported that the compassion or mindfulness-based intervention aimed to reduce psychological distress or increase well-being.

Self-Compassion

Some of the included studies used validated tools to measure self-compassion. Seven studies used the full length Neff Self-Compassion Scale [22], and four studies used the short-form version [83]. Two studies used Gilbert's Fears of Compassion Scale [84] as a secondary measure alongside the Self-Compassion Scale. Interestingly, six intervention studies did not use any self-compassion measure and all these six studies used a compassion-based intervention.

Within the eight compassion-focused intervention studies, four measured self-compassion [65,72,73,75] (and only one of these reported a significant increase in self-compassion post-intervention [72]).

In terms of qualitative data for compassion-focused interventions, there was a theme around being kinder to oneself in a study on dementia, which could relate to self-compassion, but also an acknowledgement of the guilt that can come with this [72]. In Ashworth et al.'s [70] brain injury study, self-criticism and 'revaluing self' emerged as a theme.

Seven mindfulness-based studies in this review measured self-compassion (six found an increase post-intervention [64,76,77,79–81]). One mindfulness and self-compassion combination paper did not measure self-compassion. One dementia study reported a reduction in self-compassion, quality of life and mental health post-intervention. Despite this, the qualitative feedback from participants in this study was that it was helpful in increasing their acceptance, resilience and calmness, and improving relationships [78]. Additionally, in some studies self-compassion continued to increase post-intervention, showing a larger effect at follow-up and suggesting that the process of self-compassion takes time [77,79,81].

Self-compassion was also sometimes explored by the researchers in the qualitative analyses of the mindfulness intervention studies, which were all in MS. Participants reported increased self-compassion [64,81] and increased acceptance [64] but also noted that this process developing self-compassion was challenging and gradual [79].

Psychological Distress

The most common outcomes measured alongside self-compassion were anxiety and/or depression (13 papers), followed by distress or negative affect variables (such as stress, worry, anger etc., 12 papers). Eight studies measured depression (and all reported a significant decrease in symptoms of depression post intervention regardless of intervention type [70–73,76,77,81,82]). Five studies measured distress, all using global measures of distress, (and four of these reported a significant reduction [64,67,79,81]); all of these studies used mindfulness-based interventions or a combination of mindfulness and self-compassion [67]. A study comparing CFT and ACT measured worry and resilience [68].

One study also reported an effect on anger post-intervention [82] others reported a decrease in stress (all using the same measure) [64,77,81] and one reported a decrease in catastrophizing and all-or-nothing thinking [80]. Within the eight studies that measured anxiety, the findings were mixed [64,65,69–73,80]. The papers which noted a reduction in anxiety post-intervention were all compassion-based interventions. This included two papers exploring CFT in brain injury, one of which was a case study which also included six sessions of Cognitive Behavioural Therapy [70,82]. Campbell et al. [65] measured changes in heart rate to indicate if someone was in a threatened state post-intervention (and found no effect).

Positive Aspects of Well-being

Some intervention studies measured a change in positive aspects of well-being. Interventions (particularly mindfulness-based interventions) tended to find positive changes to QoL outcomes, however findings for other positive outcomes were mixed.

Two mindfulness-related interventions noted a positive effect on the QoL of their MS sample [76,77], but in one this was minimal when measured again at 3-month follow-up [77], even though positive affect persisted at follow-up. One study suggested that there was only an effect on some aspects of QoL [64].Two compassion-focused studies investigating people with dementia which measured quality-of-life had mixed findings [71,72].

Two studies that aimed to explore the use of compassionate imagery to improve empathy in those with brain injury found no significant change in empathy post-intervention [65,75]. Other positive aspects of well-being were also measured in some studies such as mindfulness (six papers) and ACT related outcomes (four papers), and these also had mixed findings [64,76–81].

Impact on Condition

Some studies in this review measured whether interventions could impact physical outcomes or a person’s perception of their condition. The physical health variables measured included fatigue, cognition, and pain (11 papers) as well as specific disability related outcomes (six papers). In a single case study of 12-session CFT for a person with motor functional neurological disorder, Zarotti et al. [73] measured a person’s perceived impact of their condition. Additionally, other compassion-related interventions noted an effect on a person’s respiratory rate (in a dementia study) [71] or an effect on pain severity (in a migraine study) [74].

The mindfulness-related interventions measured fatigue in MS and CFS [76,80], as well as measuring any improvements in cognitive functioning following a MBSR intervention in MS [76] and functional impairment in CFS [80]. The findings regarding fatigue in mindfulness-related interventions in MS were mixed [64,76].

What are the proposed key mechanisms of change?

Despite compassion-based interventions assuming that self-compassion is the change process underlying the intervention, only four of the nine compassion-based intervention studies measured self-compassion. The study which looked at a mindfulness and self-compassion-based intervention did not measure either self-compassion or mindfulness [67]. Similarly, a study which compared ACT to CFT did not measure any potential mechanisms of change, instead just measuring resilience and worry as outcomes [68].

One study using mediation analysis reported that self-compassion mediated the relationship between the mindfulness intervention and distress [79]. It was concluded that increases in mindfulness led to more self-compassion and therefore increased the ability to regulate emotions [79]. In another mindfulness intervention, self-compassion, mindfulness, and psychological flexibility were proposed as potential mechanisms of change but mindfulness was the only factor that significantly changed immediately post-intervention, and only so only mindfulness was included in the mediation analysis [81]. However, self-compassion increased between post-intervention and follow-up, perhaps suggesting that improvements in mindfulness are needed for a change in self-compassion [81].

Discussion

This review aimed to ‘map out’ what research has been conducted on interventions using self-compassion in neurological conditions in terms of aims, conditions, methodology, theoretical models tested and general findings. Seven of the studies were RCTs, eight studies used a single group pre- and post-test design and two were case studies [73,82].

As can be seen from the papers included, compassion-focused interventions were variable in terms of the specifics of the therapy, and have been trialled in people with brain injury, migraine, dementia, and functional movement disorder. Mindfulness-related interventions appear to be more uniform, with a tendency to use a variant of MBSR/MBCT, and have been investigated in people with dementia, MS, and CFS. In both interventions examples of tailoring the therapy to the needs of the person and their condition were reported, including making adaptations to accommodate the physical and cognitive difficulties. In this review it appears that mindfulness-related interventions tend to be delivered in a group setting, whereas compassion-focused interventions appear to be more often delivered in a 1:1 setting.

Self-compassion

Five compassion-focused intervention studies in this review did not measure self-compassion (including two RCTs). The inconsistency in measuring self-compassion will limit future conclusions on whether the interventions are effective in increasing self-compassion, and the ability to attribute any change in well-being to a change in self-compassion. Additionally, this makes it difficult to ascertain whether self-compassion plays a role in the changes to distress outcomes seen or whether this can be attributed to another process. A recent review of CFT interventions in clinical populations noted that self-compassion was not always measured as a change process; instead, some studies opted to measure changes in self-criticism or self-reassurance [85]. This uncertainty around change processes has also been reported in an existing review on self-compassion interventions and physical health conditions which suggested that compassion interventions were beneficial for decreasing distress but also highlighted that there is a need to understand the process by which compassion interventions make this change [40]. Therefore, there is a need for self-compassion to be more consistently measured in neurological conditions, particularly in compassion-related interventions. Additionally, out of the five papers which reported a small sample size, four of them were compassion-focused interventions. This small sample size could have impacted the results seen, particularly in the study which did not find an increase in self-compassion [65]. This also further demonstrates that more rigorous and higher quality research is needed into compassion-focused interventions.

One MBSR study in people with dementia noted that self-compassion, quality-of-life and mental health decreased post-intervention [78]. The researchers in this study reported that the benefits participants qualitatively reported (such as acceptance and calmness) were not captured in the quantitative measures [78] and so perhaps MBSR in dementia may target outcomes or processes outside of self-compassion.

Psychological and physical health outcomes

Both types of intervention in this review measured a range of psychological and physiological outcomes. As neurological conditions can impact a person’s psychological and physical well-being [6–9], it is important to look at how psychological interventions or processes such as self-compassion could mitigate distress or adverse health outcomes. It could be helpful for future research to continue to measure psychological and physical outcomes in neurological conditions, regardless of the underlying process being investigated, as these outcomes relate to a person’s own experience of their condition and its impact on daily life.

Conditions

MS was the most researched condition in this review, despite it not being the most frequently experienced neurological condition [1]. MS was most common in the mindfulness-related intervention studies and brain injury was most common within the compassion-based intervention studies. This suggests that CFT is still being developed within neurological conditions. This is further evidenced by recent guidelines regarding mental health support in neurodegenerative conditions reporting that there is a paucity of research into therapeutic interventions in this area [86]. Given the variety of conditions seen in this review, it would be interesting for future research to consider any differences in self-compassion both quantitatively and qualitatively between degenerative conditions and conditions that do not progress or involve elements of rehabilitation.

Intervention format

The papers varied in the level of detail in their description of the intervention. This inconsistency could make it difficult for a clinician to make decisions on what intervention to carry out based on the evidence or know how to replicate this research or intervention. It also makes it difficult to ascertain whether the intervention was a CFT intervention or included some compassion elements. CFT is a non-manualised psychotherapy developed by Gilbert [87] based on his social and neurological model of compassion, which includes exercises focused on developing compassion. This differs from other manualised compassion-based therapies such as Mindful Self-Compassion [88].

Generally, the mindfulness-related interventions appeared to use existing manualised interventions such as MBSR or MBCT with some adaptations, whereas the compassion-related interventions in this review appeared less manualised. Despite this, one may argue that the core of CFT (engagement with one's suffering and taking action to prevent or alleviate this) [24] could be achieved in a variety of interventions and in the relationship between client and therapist. In fact, Gilbert [24] posits that the ‘phases’ in CFT may not be linear and a person may move between them, which could suggest that CFT is flexible and open to adaptations. CFT differs from other therapeutic approaches due to having a focus on developing competencies which enable someone to tolerate uncomfortable emotions [24]. This development of competencies could be woven into other interventions or more specifically measured in research.

Some studies took place within another program or form of care (for example, a CFT intervention within a neurorehabilitation program [70]). This makes it difficult to evidence that any change seen is solely due to the compassion intervention, and more controlled pre- and post-testing would be needed for this. However, from a clinical perspective this demonstrates how ideas from CFT can be woven into existing care and ongoing interventions, such as neurorehabilitation. At present, there is also a lack of studies comparing CFT to an alternative intervention, which hinders the ability to attribute change to CFT specifically, rather than just a psychological intervention [89]. Additionally, while individual compassion-based interventions were seen in this review, an existing review has noted that group CFT generally has more of an evidence base than individual CFT in clinical populations [89], suggesting that further research is needed exploring individual CFT interventions.

Outcome measurement

The studies which did measure self-compassion used the Neff’s Self-Compassion Scale (SCS) [22], either in its original form or short form, as their primary measure of self-compassion. It is assumed that by using the SCS, the researchers viewed self-compassion within Neff’s [21] conceptualisation of self-compassion, rather than Gilbert’s conceptualisation [90], however sometimes researchers did not explicitly state this and instead explored both concepts of self-compassion when introducing the study. The SCS measures the three dimensions of self-compassion seen in Neff's definition; self-kindness versus self-judgement, common humanity versus isolation and mindfulness versus over-identification. However, recent criticisms of this scale have included evidence suggesting that the un-compassionate components of this scale are linked to psychopathology and are in conflict with the concept of self-compassion being protective, with, therefore, the inclusion of these items in the total score being confounding [20]. The use of this measure in intervention research in particular may lead to additional difficulties, mainly because of the positive and negative components being put together in one score, which means it would be hard to ascertain what change is happing in therapy, and to what component [91]. Alternative self-compassion measures also exist (e.g. [92]), based on a recent definition of self-compassion taken from a literature review of the construct [19]. It is important that future studies consider how they are conceptualising self-compassion and that they select an outcome measurement that is aligned with this conceptualisation.

Self-compassion and time

Two intervention papers suggested that self-compassion takes time to develop as significant changes in self-compassion were only seen at longer term follow-up after an intervention [81] or increased at follow-up [79]. Bogosian et al. [79] also noted that participants qualitatively reported that developing self-compassion took time. Qualitative studies in neurological conditions have also acknowledged that processes such as grief over lost identity and acceptance of self with a neurological condition were not quick changes, and that these were aided by self-compassion [93,94]. Thus, including a longer term follow up in clinical trials of CFT seems important.

Indeed, the possibility that self-compassion takes time to develop could have impacted the two intervention studies which did not find a significant increase in self-compassion post-intervention [65,75]. Both studies involved one session of compassionate imagery for brain injury and so it is possible that this intervention was too short to make any meaningful change to self-compassion. It could be that the two compassionate imagery interventions seen in this review were not effective in those with a brain injury due to potential existing high levels of self-criticism, low levels of self-compassion or cognitive emotion-processing difficulties [95,96]. Alternatively, it could be that these interventions were too short to make a meaningful change to self-compassion, which could suggest that CFT interventions need to be longer. It is also possible that due to the high level of fear of compassion seen in both samples, the participants were unable to engage in the compassionate imagery exercise effectively [65,75]. This may suggest that fear of compassion needs to be addressed prior to any compassion-related intervention.

The idea of self-compassion taking time to develop may be interesting to explore further, as other processes such as mindfulness or psychological flexibility could overlap and interact with self-compassion, as seen in previous research exploring these relationships in non-clinical and clinical samples [97,98]. Practitioners are also beginning to examine the role self-compassion could play within ACT [99], with research also exploring mindfulness within long-term health conditions [100]. Furthermore, a recent review found that 12-sessions of CFT are needed within clinical populations generally to elicit a meaningful change, again suggesting that the development of self-compassion takes time [89].

Limitations

This review was conducted by one person and therefore there is potential for bias within the various stages of the review. This review did not include grey literature or unpublished studies, due to the time restrictions of the review and wanting to ensure some level of quality so there is the possibility that relevant papers were missed. Only papers that were published and available in English were included due to the resources of the researchers, which may have led to publication bias.

Due to the review focusing on self-compassion and therefore using ‘self-compassion’ as a search term, only papers that mentioned self-compassion were found. There could have been more research in this field with slightly different concepts such as self-criticism or self-esteem, which could be important variables to target within neurological condition interventions, but it was felt that these were beyond the scope of this review.

Future reviews in this area could evaluate the fidelity of the interventions used. Additionally, due to the nature of a scoping review and the focus of this review, the distress or well-being outcome measures used within these studies have not been fully explored. It would be helpful to look at the measures used in terms of their complexity, length, and the potential impact of this on people who already experience fatigue and/or cognitive difficulties because of their neurological condition.

Clinical implications

As previously discussed, it is possible that the process of developing self-compassion takes time, and so clinicians need to be mindful about the length of intervention they are offering, and when outcome measures for self-compassion are given. This review has highlighted examples of interventions in which practitioners have adapted their intervention to the needs of the client. This may be particularly important when working with neurological conditions, due to the physical and cognitive challenges a person may experience. This review also noted studies in which mindfulness exercises have been used in CFT or elements of compassion have been used within mindfulness, perhaps suggesting the importance of being flexible in one’s approach to working with this population. Due to the nature of a scoping review, no comparisons can be made on the effectiveness of one intervention over another.

Future research

As discussed, another scoping review is currently underway [101], looking at the role of self-compassion in neurological conditions with a focus on observational studies. It will be interesting to see how self-compassion has been explored quantitatively and qualitatively in this area and whether any findings support those seen in this intervention-focused review.

Considering that self-compassion could take time to develop, future research could explore the role of self-compassion qualitatively and quantitatively in degenerative neurological conditions, including exploring whether self-compassion changes over time as the condition progresses. Existing qualitative data in this review suggests that adjustment and acceptance could be important processes in terms of living with and managing the emotional impact of degenerative or progressive neurological condition [64,78]. It could therefore be useful for this these factors to be explored further through quantitative methodology or longitudinal qualitative methodology.

Due to self-compassion not always being measured within compassion-related interventions, the process of developing self-compassion in compassion interventions is not clear. It could be that compassion-related interventions do not increase self-compassion but instead decrease self-criticism or shame, for example, as seen in brain injury research [70]. Self-compassion has also been observed to be a mediator of the relationship between mindfulness and shame in a non-clinical sample [102], further suggesting a relationship between self-compassion and shame. Therefore, future compassion-related intervention research could measure factors such as self-criticism and shame, as well as self-compassion.

Interestingly, a recent paper ‘science mapping’ self-compassion literature found that the majority of self-compassion research focused on the mental health outcomes associated with self-compassion, with few papers exploring its relationship with physical health outcomes [103]. This suggests that future self-compassion research needs to consider the physical health outcomes of the population it is investigating. The researchers also reported that physical health papers formed the smallest ‘cluster’ of their map [103], highlighting the need for more high-quality research exploring self-compassion in health conditions or measuring physical well-being. Additionally, only one functional neurological disorder paper was found in this review and no stroke studies were found, suggesting the paucity of research in these areas and a focus for future research.

Conclusion

This review highlighted that self-compassion is being investigated in neurological conditions, however, research in this area is relatively recent and still growing. The conditions explored within self-compassion literature in mindfulness and compassion-related interventions are limited, with a focus on MS in mindfulness and brain injuries in compassion. The studies varied in methodology, including RCTs, pre and post-test design and case studies. Despite some compassion-focused studies in this review suggesting that self-compassion is an underlying change process in their intervention, the mechanism was not always measured or was not clear. Both types of interventions targeted a range of psychological and physical health outcomes. Further research is needed, including the use of RCTs and consistent measurement of self-compassion. A better understanding of the process of self-compassion development and its relationship with other internal processes, such as acceptance and mindfulness, may aid in the development of self-compassion related interventions for neurological conditions.

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Tables

Table 1-1

Database search strategies

PsycINFO [284 hits]

Section 3: Self-Compassion	**Section 4:** Neurological Conditions (Groups)	**Section 5:** Specific Conditions
Section 6: DE “Self-Compassion” OR DE “Compassion” **Section 7:** **Section 8:** Free text Self-Compassion OR Compassion*	**Section 9:** DE "Nervous System Disorders" OR DE "Autonomic Nervous System Disorders" OR DE "Central Nervous System Disorders" OR DE "Demyelination" OR DE "Head Injuries" OR DE "Hyperkinesis" OR DE "Locked-In Syndrome" OR DE "Meningoradiculitis" OR DE "Movement Disorders" OR DE "Nervous System Neoplasms" OR DE "Neurodegenerative Diseases" OR DE "Neurofibromatosis" OR DE "Neuroinflammation" OR DE "Neuromuscular Disorders" OR DE "Neuropathy" OR DE "Perceptual Disturbances" OR DE "Restless Leg Syndrome" OR DE "Sclerosis (Nervous System)" OR DE "Seizures" OR DE "Sleep Wake Disorders" **Section 10:** **Section 11:** Free text ("nervous system" OR neurologic*) N3 (condition* OR disorder* OR diseas* OR malad*)	**Section 12:** DE "Dementia" OR DE "AIDS Dementia Complex" OR DE "Dementia with Lewy Bodies" OR DE "Presenile Dementia" OR DE "Pseudodementia" OR DE "Semantic Dementia" OR DE "Senile Dementia" OR DE "Vascular Dementia" OR DE "Parkinson's Disease" OR DE "Parkinsonism" OR DE "Multiple Sclerosis" OR DE "Migraine Headache" OR DE "Cerebrovascular Accidents" OR DE "Brain Disorders" OR DE "Anencephaly" OR DE "Athetosis" OR DE "Balint's Syndrome" OR DE "Brain Damage" OR DE "Brain Death" OR DE "Brain Injuries" OR DE "Brain Neoplasms" OR DE "Cerebral Atrophy" OR DE "Cerebral Palsy" OR DE "Cerebrovascular Accidents" OR DE "Chronic Alcoholic Intoxication" OR DE "Diaschisis" OR DE "Dysexecutive Syndrome" OR DE "Encephalitis" OR DE "Encephalopathies" OR DE "Epilepsy" OR DE "Epileptic Seizures" OR DE "General Paresis" OR DE "Hydrocephalus" OR DE "Intracranial Abscesses" OR DE "Kluver Bucy Syndrome" OR DE "Leukoencephalopathy" OR DE "Microcephaly" OR DE "Organic Brain Syndromes" OR DE "Parkinson's Disease" OR DE "Tay Sachs Disease" OR DE "Cerebrovascular Disorders" OR DE "Cerebral Arteriosclerosis"

	OR DE "Cerebral Hemorrhage" OR DE "Cerebral Ischemia" OR DE "Cerebral Small Vessel Disease" OR DE "Cerebrovascular Accidents" OR DE "Subarachnoid Hemorrhage" OR DE "Cerebral Ischemia" OR DE "Cerebral Small Vessel Disease" OR DE "Coma" OR DE "Subarachnoid Hemorrhage" OR DE "Neuroinflammation" OR DE "Encephalitis" OR DE "Subarachnoid Hemorrhage" OR DE "Aneurysms" OR DE "Peripheral Neuropathy" OR DE "Guillain-Barre Syndrome" OR DE "Chronic Fatigue Syndrome" OR DE "Multiple Sclerosis" OR DE "Traumatic Brain Injury" OR DE "Brain Injuries" OR DE "Head Injuries" OR DE "Locked-In Syndrome" OR DE "Huntingtons Disease" **Section 13:** **Section 14:** Free text Epilep* OR Dementia OR FTD OR Alzheimer* OR Parkinson* OR Huntington* OR “Multiple Sclerosis” OR “Motor Neurone*” OR “Amyotrophic Lateral Sclerosis” OR “Guillain-Barre Syndrome” OR Migraine OR “Cerebrovascular N3 (Dis* OR Accident* OR Event)” OR Stroke OR “Subarachnoid Haemorrhage” OR “Intracerebral Haemorrhage” OR “Cerebral Ischemia” OR “Cerebral Small Vessel Disease” OR Encephalitis OR Poliomyelitis OR Meningitis OR “Neuroinflammation” OR “Neuropathy” OR “Chronic Fatigue*” OR “Myalgic Encephalomyelitis” OR “TBI” OR “Brain Injury” OR “ABI” OR “Head Injury” OR “Brain Dis*” OR “Brain Damage” OR “Brain Death” OR “Brain Syndromes” OR Coma OR “Locked-In Syndrome” OR “Cerebral Atrophy” OR “Cerebral Palsy” OR “Dysexecutive Syndrome” OR “Encephalopathies” OR

		“Hydrocephalus” OR “Functional N1 Neurological” OR “Conversion N1 Disorder” OR “Functional N3 Seizure*” OR “Conversion N3 Seizure*” OR “Psuedoepilep*” OR “Nonepileptic” OR “Non Epileptic” OR “Hysterical N3 (Convulsion OR Seizure*) OR “FND” OR “Functional Movement” OR “Functional (Disorder OR Disease) OR “Somatoform (Disorder OR Disease))

MEDLINE [1,601 hits]

Section 15: Self-compassion	**Section 16:** Neurological Conditions (Groups)	**Section 17:** Specific Conditions
Section 18: (MH "Self-Compassion") OR (MH "Empathy") OR TI (Self-Compassion OR Compassion*) OR AB (Self-Compassion OR Compassion*)	**Section 19:** (MH "Nervous System Diseases+") OR (MH "Autonomic Nervous System Diseases+") OR (MH "Peripheral Nervous System Diseases+") OR (MH "Central Nervous System Diseases+") OR TI (dyspraxia OR hyperkinesis OR (("nervous system" OR neurologic*) N3 (condition* OR disorder* OR diseas* OR malad*))) OR AB (dyspraxia OR hyperkinesis OR (("nervous system" OR neurologic*) N3 (condition* OR disorder* OR diseas* OR malad*))) OR (MH "Conversion Disorder+")	**Section 20:** (MH "Dementia+") OR (MH "Frontotemporal Dementia") OR (MH "Dementia, Vascular") OR (MH "Dementia, Multi-Infarct") OR (MH "AIDS Dementia Complex") OR (MH "Alzheimer Disease") OR (MH "Amyotrophic Lateral Sclerosis") OR (MH "Lewy Body Disease") OR (MH "Pick Disease of the Brain") OR (MH "Parkinsonian Disorders+") OR (MH "Parkinson Disease") OR (MH "Huntington's Disease") OR (MH "Multiple Sclerosis+") OR (MH "Migraine Disorders+") OR (MH "Stroke+") OR (MH "Cerebrovascular Disorders") OR (MH "Brain Injuries+") OR (MH "Head Injuries, Penetrating") OR (MH "Cerebral Palsy") OR (MH "Encephalitis+") OR (MH "Epilepsy+") OR (MH "Cerebrovascular Disorders") OR (MH

	"Subarachnoid Hemorrhage+") OR (MH "Neuroinflammatory Diseases") OR (MH "Guillain-Barre Syndrome") OR (MH "Fatigue Syndrome, Chronic") **Section 21:** **Section 22:** Free text (Epilep* OR Dementia OR FTD OR Alzheimer* OR Parkinson* OR Huntington* OR “Multiple Sclerosis” OR “Motor Neurone*” OR “Amyotrophic Lateral Sclerosis” OR “Guillain-Barre Syndrome” OR Migraine OR “Cerebrovascular N3 (Dis* OR Accident* OR Event)” OR Stroke OR “Subarachnoid Haemorrhage” OR “Intracerebral Haemorrhage” OR “Cerebral Ischemia” OR “Cerebral Small Vessel Disease” OR Encephalitis OR Poliomyelitis OR Meningitis OR “Neuroinflammation” OR “Neuropathy” OR “Chronic Fatigue*” OR “Myalgic Encephalomyelitis” OR “TBI” OR “Brain Injury” OR “ABI” OR “Head Injury” OR “Brain Dis*” OR “Brain Damage” OR “Brain Death” OR “Brain Syndromes” OR Coma OR “Locked-In Syndrome” OR “Cerebral Atrophy” OR “Cerebral Palsy” OR “Dysexecutive Syndrome” OR “Encephalopathies” OR “Hydrocephalus” OR “Functional N1 Neurological” OR “Conversion N1 Disorder” OR “Functional N3 Seizure*” OR “Conversion

		N3 Seizure*" OR "Psuedoepilep*" OR "Nonepileptic" OR "Non Epileptic" OR "Hysterical N3 (Convulsion OR Seizure*) OR "FND" OR "Functional Movement" OR "Functional (Disorder OR Disease) OR "Somatoform (Disorder OR Disease))

CINAHL [320 hits]

Section 23: Self-Compassion	**Section 24:** Neurological Conditions (Groups)	**Section 25:** Specific Conditions
Section 26: (MH "Self-Compassion") OR (MH "Compassion") OR TI (Self-Compassion OR Compassion*) OR AB (Self-Compassion OR Compassion*)	**Section 27:** (MH "Neurodegenerative Diseases+") OR (MH "Gait Disorders, Neurologic+") OR (MH "Autoimmune Diseases of the Nervous System+") OR (MH "Central Nervous System Viral Diseases+") OR (MH "Nervous System Neoplasms") OR (MH "Nervous System Abnormalities") OR TI (dyspraxia OR hyperkinesis OR (("nervous system" OR neurologic*) N3 (condition* OR disorder* OR diseas* OR malad*))) OR AB (dyspraxia OR hyperkinesis OR (("nervous system" OR neurologic*) N3 (condition* OR disorder* OR diseas* OR malad*))	**Section 28:** (MH "Dementia+") OR (MH "Alzheimer's Disease") OR (MH "Parkinson Disease") OR (MH "Huntington's Disease") OR (MH "Multiple Sclerosis+") OR (MH "Migraine") OR (MH "Stroke+") OR (MH "Cerebrovascular Disorders") OR (MH "Brain Injuries+") OR (MH "Encephalitis+") OR (MH "Cerebral Palsy") OR (MH "Cerebral Ischemia+") OR (MH "Hypoxia-Ischemia, Brain+") OR (MH "Bell Palsy") OR (MH "Cerebral Hemorrhage") OR (MH "Epilepsy+") OR (MH "Subarachnoid Hemorrhage") OR (MH "Neuroinflammation") OR (MH "Guillain-Barre Syndrome+") OR (MH "Fatigue Syndrome, Chronic") **Section 29:** **Section 30:** Free text (Epilep* OR Dementia OR FTD OR Alzheimer* OR Parkinson* OR Huntington* OR "Multiple Sclerosis" OR "Motor Neurone*" OR "Amyotrophic Lateral

		Sclerosis” OR “Guillain-Barre Syndrome” OR Migraine OR “Cerebrovascular N3 (Dis* OR Accident* OR Event)” OR Stroke OR “Subarachnoid Haemorrhage” OR “Intracerebral Haemorrhage” OR “Cerebral Ischemia” OR “Cerebral Small Vessel Disease” OR Encephalitis OR Poliomyelitis OR Meningitis OR “Neuroinflammation” OR “Neuropathy” OR “Chronic Fatigue*” OR “Myalgic Encephalomyelitis” OR “TBI” OR “Brain Injury” OR “ABI” OR “Head Injury” OR “Brain Dis*” OR “Brain Damage” OR “Brain Death” OR “Brain Syndromes” OR Coma OR “Locked-In Syndrome” OR “Cerebral Atrophy” OR “Cerebral Palsy” OR “Dysexecutive Syndrome” OR “Encephalopathies” OR “Hydrocephalus” OR “Functional N1 Neurological” OR “Conversion N1 Disorder” OR “Functional N3 Seizure*” OR “Conversion N3 Seizure*” OR “Psuedoepilep*” OR “Nonepileptic” OR “Non Epileptic” OR “Hysterical N3 (Convulsion OR Seizure*) OR “FND” OR “Functional Movement” OR “Functional (Disorder OR Disease) OR “Somatoform (Disorder OR Disease))

AMED [20 hits]

Section 31: Self-Compassion	**Section 32:** Neurological Conditions (Groups)	**Section 33:** Specific Conditions

Section 34: TI (Self-Compassion OR Compassion*) OR AB (Self-Compassion OR Compassion*)	**Section 35:** ((ZU "neurological rehabilitation"))) or ((ZU "neuromuscular dis")))	**Section 36:** ((ZU "conversion disorder")) or ((ZU "epilepsy"))) or ((ZU "dementia"))) or ((ZU "parkinson dis"))) or ((ZU "huntingtons dis"))) or ((ZU "multiple sclerosis"))) or ((ZU "guillain barre syndrome") or (ZU "guillain-barre syndrome"))) or ((ZU "migraine"))) or ((ZU "cerebrovascular accident") or (ZU "cerebrovascular disorders"))) or ((ZU "stroke"))) or ((ZU "brain ischemia"))) or ((ZU "subarachnoid hemorrhage"))) or ((ZU "encephalitis"))) or ((ZU "cerebral palsy")) **Section 37:** **Section 38:** Free text (Epilep* OR Dementia OR FTD OR Alzheimer* OR Parkinson* OR Huntington* OR “Multiple Sclerosis” OR “Motor Neurone*” OR “Amyotrophic Lateral Sclerosis” OR “Guillain-Barre Syndrome” OR Migraine OR “Cerebrovascular N3 (Dis* OR Accident* OR Event)” OR Stroke OR “Subarachnoid Haemorrhage” OR “Intracerebral Haemorrhage” OR “Cerebral Ischemia” OR “Cerebral Small Vessel Disease” OR Encephalitis OR Poliomyelitis OR Meningitis OR “Neuroinflammation” OR “Neuropathy” OR “Chronic Fatigue*” OR “Myalgic Encephalomyelitis” OR “TBI” OR “Brain Injury” OR “ABI” OR “Head Injury” OR “Brain Dis*” OR “Brain Damage” OR “Brain Death” OR “Brain Syndromes” OR Coma OR “Locked-In Syndrome” OR “Cerebral Atrophy” OR “Cerebral Palsy” OR “Dysexecutive Syndrome” OR

		“Encephalopathies” OR “Hydrocephalus” OR “Functional N1 Neurological” OR “Conversion N1 Disorder” OR “Functional N3 Seizure*” OR “Conversion N3 Seizure*” OR “Psuedoepilep*” OR “Nonepileptic” OR “Non Epileptic” OR “Hysterical N3 (Convulsion OR Seizure*) OR “FND” OR “Functional Movement” OR “Functional (Disorder OR Disease) OR “Somatoform (Disorder OR Disease))

Web of Science [532 hits]

Section 39: Self-Compassion	**Section 40:** Neurological Conditions (Groups)	**Section 41:** Specific Conditions
Section 42: TI “Self-Compassion” OR “Compassion*” AB “Self-Compassion” OR “Compassion*”	**Section 43:** TI (("nervous system" OR neurologic*) NEAR/3 (condition* OR disorder* OR diseas* OR malad*)) OR AB (("nervous system" OR neurologic*) NEAR/3 (condition* OR disorder* OR diseas* OR malad*))	**Section 44:** Free text (Epilep* OR Dementia OR FTD OR Alzheimer* OR Parkinson* OR Huntington* OR “Multiple Sclerosis” OR “Motor Neurone*” OR “Amyotrophic Lateral Sclerosis” OR “Guillain-Barre Syndrome” OR Migraine OR “Cerebrovascular NEAR/3 (Dis* OR Accident* OR Event)” OR “Stroke” OR “Subarachnoid Haemorrhage” OR “Intracerebral Haemorrhage” OR “Cerebral Ischemia” OR “Cerebral Small Vessel Disease” OR “Encephalitis” OR “Poliomyelitis” OR “Meningitis” OR “Neuroinflammation” OR “Neuropathy” OR “Chronic Fatigue*” OR “Myalgic Encephalomyelitis” OR “TBI” OR “Brain Injury” OR “ABI” OR “Head Injury” OR “Brain Dis*”

	OR “Brain Damage” OR “Brain Death” OR “Brain Syndromes” OR “Coma” OR “Locked-In Syndrome” OR “Cerebral Atrophy” OR “Cerebral Palsy” OR “Dysexecutive Syndrome” OR “Encephalopathies” OR “Hydrocephalus” OR “Functional NEAR/1 Neurological” OR “Conversion NEAR/1 Disorder” OR “Functional NEAR/3 Seizure*” OR “Conversion NEAR/3 Seizure*” OR “Psuedoepilep*” OR “Nonepileptic” OR “Non Epileptic” OR “Hysterical NEAR/3 (Convulsion OR Seizure*)” OR “FND” OR “Functional Movement” OR “Functional (Disorder OR Disease)” OR “Somatoform (Disorder OR Disease)”)

Table 1-2

Data extraction table

Study; Country	Sample N (%male, Mean age); setting	Study design; analysis	Condition	Self-compassion measure used	Correlates or outcomes with measures used	Summary; Findings
Ashworth, F et al. 2011; UK	1 (0%, 20); Neurorehabilitation centre.	Case Study, 1:1 CFT intervention alongside neurorehabilitation program. No information on whether therapy was F2F or remote; comparison of pre- and post-questionnaires using reliable change indices.	TBI	None	Anxiety- BAI; Depression- BDI; Self-concept- SCQ; Anger- STAXI. Neuropsychological assessments Client-rated key cognitions 0-100%.	Initial 6 sessions of therapy were CBT focused but this did not address her low self-esteem so sessions 7-24 were CFT focused. Aim was to encourage activation of self-soothing system and regulation of self-criticism. Clinically meaningful reduction in anxiety and depression. Increase in self-esteem, decrease in anger expression. Key cognition ratings such as 'I am worthless' reduced. Client reported that they had returned to work and felt more comfortable socialising.
Ashworth, F et al. 2015; UK	12 (58%, 46.1 male/ 33.5 female); Neurorehabilitation outpatient programme.	Naturalistic mixed-methods, CFT group based and 1:1 intervention. No information on whether therapy was F2F or remote;	ABI	None	Anxiety and depression- HADS Self-criticism and self-reassurance- FSCRS	CFT intervention as part of a 'mood group', which was week 6 of an 18-week neurorehabilitation programme. Participants also received 1:1 CFT (maximum 18 sessions).

		comparison of pre- and post-program self-report measures and IPA for interviews.				Significant reduction in; hated and inadequate self, anxiety and depression. Significant increase in reassured self. Authors report that reassured self relates to being self-compassionate. Large effect sizes reported for all outcomes. Self-compassion was not a theme in qualitative findings, but self-criticism was and so was ‘revaluing self’.
Barchakh et al. 2021; Iran	30 (20%, 34.43); patients referred to a certain hospital with migraines between May-July 2019.	Compassion intervention, unclear whether 1:1 or group-based, unclear whether F2F or remote, quantitative; comparisons of pre- and post-intervention measures, ANCOVA, MANCOVA.	Migraine	None.	Emotional Control- ECQ Pain Severity- GSCP Migraine Disability- MIDAS	Randomly allocated into control group (*N*=15) or experimental group (*N*=15). Experimental group received 8 x 90-minute sessions of CFT. Improvement in emotional control and reduction in pain severity post-intervention. Reported that 75% of variance in emotional control and 39% of the variance in pain severity was explained by the intervention.

Berk et al. 2019; Netherlands	14- 7 dyads (50%, 71.11); recruited from case managers and local advertisements.	MBSR intervention, group based, F2F, mixed methods; comparison of self-report questionnaires pre- and post-intervention and interviews. Mean difference and effect size for quantitative data, deductive content analysis for qualitative.	Dementia	SCS-SF	Quality of Life- WHOQOL-Brief Caregiver Burden- SPPIC Positive Mental Health- MHC-SF Worry- PSWQ Psychological Distress- DASS-21 Mindfulness- FFMQ-SF	TANDEM training, "Attention Training for People with Dementia and their Caregivers", based on the Mindfulness-based Stress Reduction Program. 8 sessions. Increase in mindfulness post-intervention for carers but not the person with dementia. Reduction in self-compassion, quality of life and mental health post-intervention for people with dementia. Qualitative analysis suggested that group was helpful in increasing acceptance, resilience and calmness, as well as positively impacting their relationship.
Blankespoor et al. 2017; Netherlands	25 (16%, 52.64); recruited volunteers from a mindfulness study day for MS patients held at a university.	MBSR group intervention, no information on whether therapy was F2F or remote, quantitative, comparison of pre- and post-intervention questionnaires and cognitive tests.	Multiple Sclerosis	SCS	Depression- BDI MS Quality of Life- MSQL-54 Fatigue- CIS-F Mindfulness- FFMQ 6 Neuropsychological tests.	The intervention was MBSR-Mindfulness-based Stress Reduction program, and this took place over 8 sessions. Post-intervention, there was a significant increase in self-reported mindfulness, quality of life and self-compassion

						(particularly an increase in self-kindness and reduction in over-identification). There was a significant reduction in depression and fatigue. Minimal improvements in cognitive functioning.
Bogosian et al. 2016; UK	40 (47.4%, 53.42); advertisement through MS charities and NHS centres across UK.	Mindfulness intervention. Group-based intervention delivered via videoconferencing. Mixed methods, pilot RCT and qualitative interview following intervention; mediation analysis and deductive thematic analysis.	Multiple Sclerosis	SCS-SF	Outcome: General distress- GHQ-12 Mediators: Acceptance- AAQ-II Decentring- EQ Disease Management-SEMCD Disability Status-EDSS	Participants assigned to mindfulness group (*N*= 19) or control group (*N*= 21) and matched based on demographic and illness-related information. Qualitative- participants reported increased compassion towards themselves but also that the process towards self-compassion was challenging and took time. Quantitative- small to medium mediation effect of self-compassion for the intervention to reduce distress. Largest mediating effect was decentring.
Campbell et al. 2019; UK	24 (83%, 47); recruitment through NHS services and a	Compassion intervention, 1:1 F2F, quantitative;	Head Injury	SCS	Fears of Compassion Scale -FoC	Participants randomly allocated to brief compassion focused

	charity community group	Comparison of pre- and post-intervention scores, ANCOVA			Motivation for Intervention Scale - MIS Negative Affect from PNAS Anxiety- STAI Empathy Quotient Heart Rate Variability	imagery group or relaxation imagery group. There were no significant relationships found between empathy quotient or self-compassion and heart rate variability. There were no significant changes found in self-compassion when comparing pre- and post-intervention scores. There was an increase in relaxation and decrease in anxiety when groups were pooled, but this was not related to self-compassion.
Campbell et al. 2021; Australia	126 (15.07%, 51.83); 75 completed post-intervention questionnaires; recruitment through MS society advertising	Mindfulness intervention, group intervention, unclear of location of intervention, mixed methods; comparison of pre- and post - intervention scores, ANOVA, regression, mediation. Thematic analysis for qualitative data.	Multiple Sclerosis	SCS	Distress- DASS-21 Fatigue- MFIS Perceived Stress- The Perceived Stress Scale (PSS) Quality of Life- SF-36 Psychological Flexibility- AAQ-II Mindfulness- FFMQ-SF MS Disease Severity- Physician’s Disease Steps Scale Disability- Activities of Daily Living Self-Care Scale for PwMS.	Brief mindfulness intervention for MS delivered over 5 years in the community. Mindfulness programme was adapted from MBSR. Programme was 5 2-hour weekly sessions. Statistically significant reduction in distress, stress and depression post-intervention. In terms of change mechanisms there was a significant main effect for self-compassion, mindfulness and

						psychological flexibility. Self-compassion increased between post-intervention and follow-up. However, mindfulness was the only factor proposed as a change mechanism that significantly changed pre to post intervention and so only this could be used in temporal mediation analysis. Increased self-compassion emerged as a theme in qualitative data.
Collins et al. 2018; UK	64 participants/ 32 dyads. Patients: 32 (62.5%, 74.12); recruited from a memory assessment service.	Compassion intervention, group based F2F, quantitative; comparison of pre- and post-intervention measures.	Dementia	None.	Anxiety and Depression- HADS Respiratory Rate. The Quality of Life in Alzheimer's Disease Questionnaire.	CFT group intervention for people with dementia and their spouses. The intervention was 6 sessions, 2 hours each, over 6 weeks. 10 groups completed the intervention between 2013-2017. There was a significant reduction in depression scores and respiratory rate for those with dementia, but the reduction in anxiety scores was not significant. There was a significant increase in quality of life with a large effect size.

						Self-compassion not measured.
Craig et al. 2018; UK	7 (14%, 76.6); recruited from memory services and dementia charity.	Compassion intervention, 1:1, unclear if F2F or remote, development and feasibility study; mixed methods case series, RCI for each measure. Thematic analysis for interviews.	Dementia	SCS-SF	Anxiety- RAID Quality of Life- Alzheimer's Disease Session Rating Scale	Development of CFT intervention for people with dementia. 5 participants completed all 10 sessions of the intervention. Self-compassion increased for all participants. Minimal change on QoL measure. Reductions in depression and anxiety but no clinically significant reduction in anxiety. Qualitative data showed a theme of being kinder to self, but one participant noted guilt around being kind to self. Study reported that CFT could not be covered well in 10 sessions and requires at least 12.
Künzi et al. 2022; Switzerland	Animal assisted group: 14 (64.30%, 42.36) Without animals: 17 (70.60%, 45.47)	Intervention, group based F2F, quantitative; comparison of pre- and post-measures	ABI	None	Distress- Global Severity Index	This study compared two groups of a mindfulness and self-compassion-based group intervention, one with animal-assistance and one without.

	Recruited from inpatient neurorehabilitation.					There was a significant decrease in psychological distress post-intervention in both groups. There was no significant difference between the with and without animal groups.
MirMoeini et al. 2022; Iran	45 participants. 15 assigned to ACT group. 15 to CFT group and 15 to control group (more females than males, 28.84); recruited from a MS clinic	Quantitative, intervention, unclear if group-based or 1:1 and where this intervention took place, quasi-experimental; MANCOVA	Multiple Sclerosis	None	Resilience- Conner and Davidson Resilience Questionnaire Worry-Pennsylvania Concern Questionnaire	This study aimed to compare Acceptance and Commitment Therapy with Compassion Focused Therapy for people with MS. There was a significant difference between the control group and both intervention groups. Both CFT and ACT decreased worry and increased resilience. ACT appeared more effective than CFT.
O’Neill et al. 2012; UK	Imagery group: 12 (16.67%, 45.33) Relaxation group: 12 (8.33%, 39.08). Recruited from voluntary TBI support groups and rehabilitation services.	Quantitative, 1:1 F2F, compassion intervention; comparison of pre- and post-measures, ANCOVA	TBI	SCS	Basic Empathy Scale Balanced Emotional Empathy Scale Fears of Compassion Scales The Empathy Quotient	This study explored whether a single session of compassionate imagery could improve empathy in those with low empathy following a head injury. There was an increase in self-compassion, but this was not significant, and this was across both groups. No effect was

						found on empathy from a session of compassionate imagery.
Rimes et al. 2013; UK	MCBT group: 16 (25%, 41.4) Waitlist group: 19 (10.52%, 45.2) Recruited from an NHS service where participants had completed CBT the previous year.	Quantitative, pilot study for mindfulness intervention, group F2F intervention; comparison of pre- and post-intervention measures	Chronic Fatigue Syndrome	SCS	Fatigue- Chalder Fatigue Scale Physical Functioning Scale The Beliefs about Emotions Scale Impairment- The Work and Social Adjustment Scale Anxiety/depression- HADS Mindfulness- FFMQ	This was a pilot study for a mindfulness-based cognitive therapy (MBCT) intervention for those with CFS. The MCBT had larger positive outcomes than the waiting list group on: lower fatigue, impairment, depressive symptoms, catastrophizing, all-or-nothing responses, beliefs about emotions, mindfulness and self-compassion.
Simpson et al. 2017; UK	Intervention group: 25 (8%, 43.6) Control group: 25 (22%, 46.3); recruited from NHS clinics, MS society websites and social media.	Quantitative, mindfulness intervention, group based F2F; ANCOVA	Multiple Sclerosis	SCS- SF	Mindfulness- Mindful Attention Awareness Scale (MAAS) Stress- PSS-10 Quality of life- EQ-5D-3L Fatigue- MFIS Mental health- Mental Health Inventory	This study aimed to test the feasibility of a mindfulness-based stress reduction (MBSR) course for people with MS. There was a large positive effect post-intervention on, perceived stress, depression, positive affect and self-compassion. There was a small positive effect on quality of life. At a three-month follow-up the

					Modified Social Support Survey Cognitive function- Perceived Deficits Questionnaire Pain- Pain Effects Scale Visual function, bladder function, bowel function and sexual satisfaction measures	improvement on perceived stress had decreased and impact on quality of life was minimal. However, effects remained large for mindfulness, positive affect, and self-compassion.
Spitzer et al. 2018; Australia	23 (8.7%, 48.4); recruited through an MS organisation.	Mixed-methods, mindfulness intervention, group-based, F2F; MANOVA, thematic analysis	Multiple Sclerosis	SCS	Disability- Physician's Disease Steps Scale Distress- DASS-21 Stress- PSS-10 Quality of life- SF-36 Fatigue- MFIS-5 Acceptance- AAQ-II Mindfulness- FFMQ-SF	This study examined a brief community mindfulness program for people with MS. Mindfulness program was adapted from MBSR and MBCT. Post-intervention, there was a decrease in distress and perceived stress and an increase in self-compassion, mindfulness, and acceptance. Anxiety, fatigue and some aspects of QoL did not decrease. Qualitative data included themes of increased self-compassion and acceptance.

Zarotti et al. 2022; UK	1 (100%, 81); clinical case study within an older adult psychology service	Quantitative, case study, 1:1 F2F compassion intervention; pre- and post-measure comparison, reliable change index.	Motor Functional Neurological Disorder	SCS	Perceived impact of mFND- Psychological Outcome Profiles Anxiety/depression- HADS	This was a case study to assess the impact of a 12-session CFT intervention for an older adult with Motor Functional Neurological Disorder. The patient's perceived impact of mFND decreased post-intervention. His scores on the anxiety and depression measure also reduced to under the clinically significant range, with a reliable change for depression. There was an improvement in his scores in self-compassion but there was no reliable change.

Table 1-3

Quality Appraisal

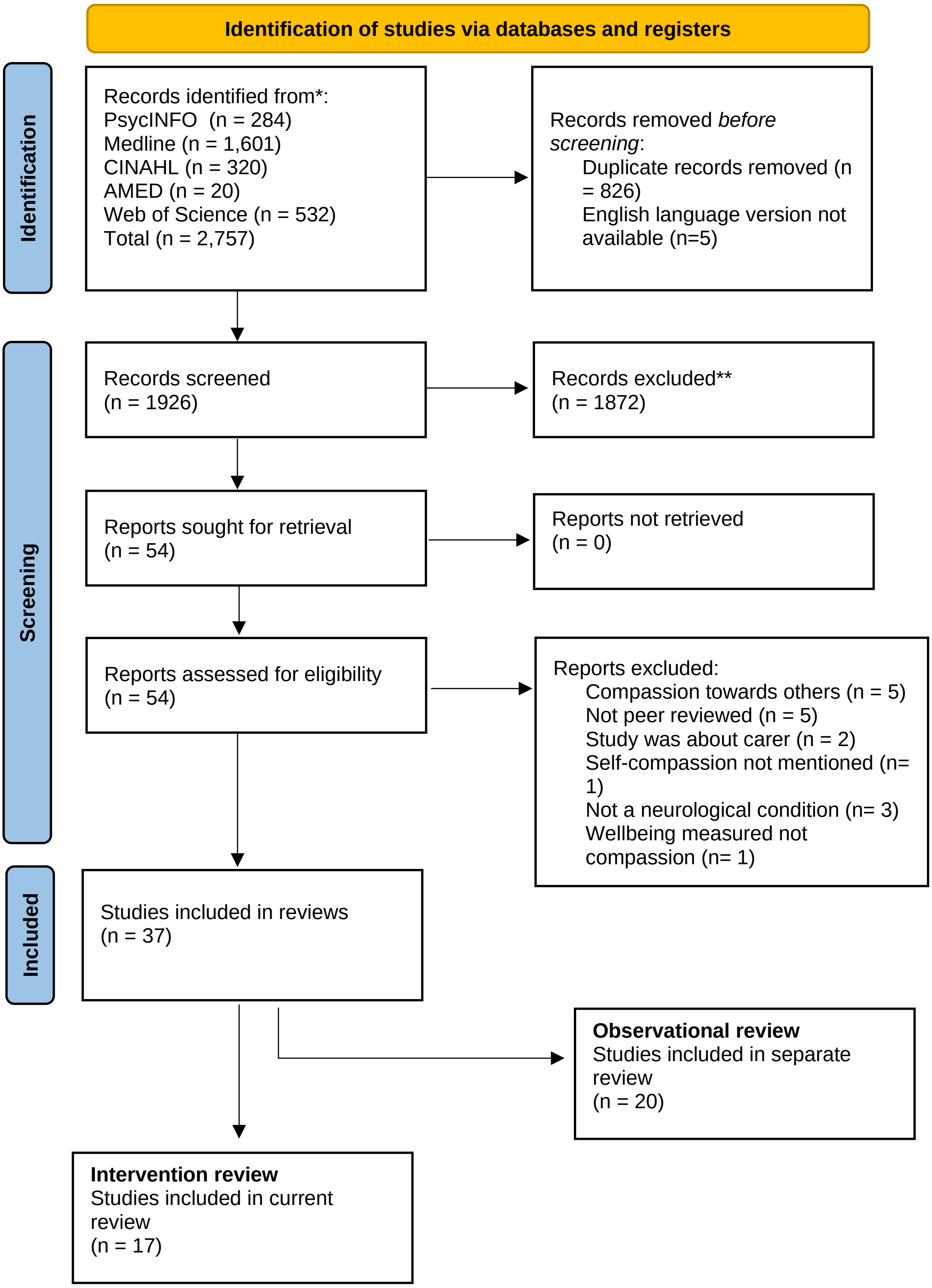
Paper	1	2	3	4	5	6	7	8	9	10	11	12	13	14	Total	Poss Score	Score
Ashworth, F et al. 2011	1	1	n/a	2	n/a	n/a	n/a	1	n/a	1	2	1	2	1	12	18	0.67
Ashworth, F et al. 2015	1	2	1	2	n/a	n/a	n/a	2	0	2	2	1	2	2	17	22	0.77
Barchakh et al. 2021	2	2	2	1	1	n/a	n/a	2	0	2	2	1	2	1	18	24	0.75
Berk et al. 2019	2	2	1	2	n/a	n/a	n/a	1	0	2	2	0	2	2	16	22	0.73
Blankespoor et al. 2017	2	1	1	2	n/a	n/a	n/a	2	1	2	2	1	2	2	18	22	0.82
Bogosian et al. 2016	2	2	2	2	2	n/a	n/a	2	2	2	2	2	2	2	24	24	1.00
Campbell et al. 2019	2	2	1	2	2	2	2	2	0	2	1	1	2	2	23	28	0.82
Campbell et al. 2021	2	2	2	2	n/a	n/a	n/a	2	2	2	2	1	2	2	21	22	0.95
Collins et al. 2018	2	2	1	2	n/a	n/a	n/a	2	1	2	2	1	2	2	19	22	0.86
Craig et al. 2018	2	1	2	1	n/a	n/a	n/a	1	0	1	1	1	2	1	13	22	0.59
Künzi et al. 2022	1	2	2	2	2	n/a	n/a	2	2	2	2	1	2	2	22	24	0.92
MirMoeini et al. 2022	1	1	1	1	1	n/a	0	1	1	2	2	0	1	1	13	26	0.50
O'Neill et al. 2012	2	2	2	2	2	n/a	0	2	2	2	2	2	2	2	24	26	0.92
Rimes et al. 2013	2	2	1	2	2	n/a	n/a	2	1	2	2	2	2	2	22	24	0.92
Simpson et al. 2017	1	2	2	2	2	n/a	n/a	2	1	2	2	2	2	2	22	24	0.92
Spitzer et al. 2018	1	2	1	2	n/a	n/a	n/a	2	1	2	2	1	2	2	18	22	0.82
Zarotti et al. 2022	1	2	n/a	2	n/a	n/a	n/a	2	n/a	2	0	1	2	2	14	18	0.78

Note: The tool used is the 'Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields'. Item 1: Question / objective sufficiently described? 2: Study design evident and appropriate? 3: Method of subject/comparison group selection or source of information/input variables described and appropriate? 4: Subject (and comparison group, if applicable) characteristics sufficiently described? 5: If interventional and random allocation was possible, was it described? 6: If interventional and blinding of investigators was possible, was it reported? 7: If interventional and blinding of subjects was possible, was it reported? 8: Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias?

Means of assessment reported? 9: Sample size appropriate? 10: Analytic methods described/justified and appropriate? 11: Some estimate of variance is reported for the main results? 12: Controlled for confounding? 13: Results reported in sufficient detail? 14: Conclusions supported by the results?

N/A: Not applicable. Scores as follows: 2 (yes), 1 (partial), 0 (no).

Figure 1-1: Study search flow chart



From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

Appendix 1-1

Author Guidelines for Disability and Rehabilitation

Instructions for authors

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**Usage in 2018-2020 for articles published in 2016-2020.

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2. A structured **abstract** of no more than 200 words. A structured abstract should cover (in the following order): the *purpose* of the article, its *materials and methods* (the design and methodological procedures used), the *results* and conclusions (including their relevance to the study of disability and rehabilitation). Read tips on writing your abstract.
3. You can opt to include a **video abstract** with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.
4. 5-8 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.
5. A feature of this journal is a boxed insert on **Implications for Rehabilitation**. This should include between two to four main bullet points drawing out the implications for rehabilitation for your paper. This should be uploaded as a separate document. Below are examples:

   Example 1: Leprosy

   - Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.
   - Reconstructive surgery is a technique available to this group.
   - In a relatively small sample this study shows participation and social functioning improved after surgery.

Example 2: Multiple Sclerosis

- Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).
- People with MS have complex reasons for choosing to exercise or not.
- Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.

6. **Acknowledgement**. Please supply all details required by your funding and grant-awarding bodies as follows: *For single agency grants*: This work was supported by the under Grant . *For multiple agency grants*: This work was supported by the under Grant ; under Grant ; and under Grant .

7. **Declaration of Interest**. This is to acknowledge any financial or non-financial interest that has arisen from the direct applications of your research. If there are no relevant competing interests to declare please state this within the article, for example: *The authors report there are no competing interests to declare.* Further guidance on what is a conflict of interest and how to disclose it.

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11. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour). Figures should be saved as TIFF, PostScript or EPS files.

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Queries

Should you have any queries, please visit our Author Services website or contact us here.

Updated 12-11-2021

Appendix 1-2

PRISMA-ScR Checklist

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	1-1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	1-2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	1-6; 1-7
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	1-6; 1-8
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	1-7
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	1-9
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	1-8; 1-9
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	1-41
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	1-9; 1-10
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	1-10; 1-11
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	1-8; 1-9

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	1-7
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	1-10
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	1-95
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	1-11; 1-12
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	1-16
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	1-11 – 1-19
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	1-11 – 1-19
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	1-22 – 1-28
Limitations	20	Discuss the limitations of the scoping review process.	1-20
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	1-20- 1-25
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	N/A

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 2018;169:467–473. doi: 10.7326/M18-0850.

Section 2: Empirical Paper

The Role of Self-Compassion and Experiential Avoidance in Functional Seizures

Word count (excluding references, appendices, and tables): 7,991

Megan Hawkes

Lancaster University Doctorate in Clinical Psychology

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Target journal for publication is Epilepsy & Behavior

All correspondence should be sent to:

Megan Hawkes
Doctorate in Clinical Psychology
Health Innovation One
Lancaster University
LA1 4AT
Email: m.hawkes@lancaster.ac.uk

Abstract

Research into self-compassion is beginning to demonstrate its importance in terms of psychological well-being in those with long-term conditions. However, less is known about the role of self-compassion in functional seizures. This study aimed to explore the relationships between self-compassion, experiential avoidance, and outcomes (depression, quality-of-life, seizure severity and seizure frequency) in functional seizures. Seventy-six participants with functional seizures completed an online survey of quantitative measures. The results indicated that increases in self-compassion were associated with decreases in experiential avoidance, seizure severity and depression symptoms, and increases in quality-of-life, but were not associated with seizure frequency. An increase in experiential avoidance was related to an increase in seizure severity, depression symptoms, and seizure frequency, as well as a decrease in self-compassion and quality-of-life. Experiential avoidance was found to mediate the relationships between self-compassion and quality-of-life, seizure severity and depression symptoms. Potential clinical implications for working with functional seizures and ideas for future research are discussed.

Keywords: Functional Seizures, Functional Neurological Disorder, Self-compassion, Experiential Avoidance

Introduction

Functional seizures can present with a similar set of symptoms to that of epileptic seizures including paroxysmal, focal, and sensory events. However, functional seizures differ from epileptic seizures in that they do not present with the EEG abnormalities seen in epilepsy [1]. The terminology used to describe functional seizures is inconsistent in research, with the condition also being referred to as non-epileptic attack disorder (NEAD), psychogenic nonepileptic seizures (PNES) and occasionally ‘dissociative seizures’ or ‘conversion disorder’. Despite this, there is a move towards the more neutral term of ‘functional seizures’ [2] and so, this terminology will be used throughout this paper. The prevalence of functional seizures is not clearly reported, but one paper suggests that between 10-20% of people referred to epilepsy clinics are diagnosed with functional seizures [3]. However, there are difficulties in reporting the epidemiology of functional seizures due to inconsistencies in diagnostic criteria, small-scale studies and a lack of cross-cultural comparisons [4].

The underlying mechanisms of functional seizures are debated. Historically, research suggested that functional seizures could be explained through somatization of distress or dissociation [5]. However, more recently, an ‘Integrative Cognitive Model’ of functional seizures has been proposed [6]. This model suggests that a person’s prior experience and internal ‘model’ of a seizure (represented as the ‘seizure scaffold’) is triggered by a person’s environment, stimuli, or thoughts. The researchers suggest that this is comparable to a conditioned reflex and the activation of this seizure scaffold is typically in response to heightened arousal which could be due to distress or other factors such as physical illness or medication [6]. This model acknowledges that psychological distress, life stressors, physical health and prior trauma could contribute to functional seizures, whilst noting that seizures can still occur in the absence of these factors.

A proportion (although not all) of those experiencing functional seizures report also experiencing a history of trauma [7]. Childhood trauma is more often reported in those with functional seizures when compared to those with epilepsy [8] and a history of trauma is reportedly more prevalent in those with functional seizures than in those who have other functional neurological symptoms [9]. However, more recent research has also suggested the presence of a trauma history or recent traumatic stress in those with various functional neurological disorders, not just functional seizures [10,11].

The presence of depression or anxiety and their associated diagnoses are frequently measured and reported in functional seizure research. A large-scale study reported that 69% of their functional seizure sample had a psychiatric diagnosis [12]. Individuals with functional seizures are more likely to report anxiety, depression or a ‘mood disorder’ than those with epilepsy [13–15], although one study noted no significant difference in depression scores but did report the functional seizure group had higher levels of physiological symptoms [16]. Other studies have noted no significant difference between functional seizure and epilepsy groups on scores of depression, but have reported that the functional seizure group reported higher anxiety [17].

Functional seizures can be debilitating, often having a large impact on a person’s quality-of-life in addition to the psychological difficulties described. People with functional seizures report a lower quality-of-life than those with epilepsy [18–20]. Lower quality-of-life is related to higher depressive symptoms [21], higher anxiety [22], increased illness perception [19] and higher perceived stigma [23] in functional seizures. Research has begun to explore potential predictors of quality-of-life in functional seizures such as age of onset of functional seizures, duration of the seizures, anger expression [24] and potential mediators such as somatisation [20].

One potentially important psychological construct for people who experience functional seizures is avoidance. Experiential avoidance can be described as a reluctance to experience difficult feelings, thoughts and sensations and engaging in attempts to control or escape these experiences [25]. It is suggested that by attempting to inhibit these uncomfortable feelings, thoughts, and sensations, one can inadvertently increase the frequency and distress of these experiences [26,27]. Experiential avoidance has been commonly found in those with functional seizures [28] and research has suggested this group have more avoidant coping styles than controls [29–31]. Engaging in experiential avoidance is linked to higher levels of psychological distress [32–34] in clinical and non-clinical populations and can reduce the ability to experience positive emotions or events [35]. The anxiety and avoidance a person with functional seizures experiences could also impact the frequency of their seizures [36]. Therefore, experiential avoidance could be linked to both physical and psychological outcomes in both those with functional seizures and other samples.

Whilst a multitude of variables can influence a person’s wellbeing, one that has emerged in recent literature is self-compassion. Compassion can be described as a sensitivity to suffering in ourselves and others, with a commitment to try to alleviate and prevent it [37–39]. Gilbert [37] suggests that compassion is a ‘social mentality’ that can flow in three directions including the compassion we feel towards ourselves (self-compassion). A systematic review of clinical and non-clinical samples demonstrated that low levels of self-compassion were associated with an increase in anxiety and depression and a decrease in well-being and resilience [40]. Additionally, whilst the ‘protective’ mechanism of self-compassion is not yet clear, there is a suggestion that self-compassion can ‘buffer’ against post-traumatic stress disorder symptoms [41] and that experiencing childhood trauma could lead to an increased fear of self-compassion [42]. Therefore, it could be important to examine self-compassion within a population where trauma experience is highly prevalent, such as functional seizures.

In those with physical health conditions, high self-compassion has been seen to relate to outcomes such as reduced anxiety and depression [43], reduced shame [44] and increased adherence to medical recommendations [45]. One study reported that higher self-compassion was related to lower levels of stress through coping style (both adaptive and maladaptive) [46] suggesting that self-compassion influences the type of coping a person adopts and this then leads to more or less stress. The role of self-compassion has also been explored in neurological conditions, and similar relationships have been found, such as the relationship between higher self-compassion and higher quality-of-life in multiple sclerosis [47] or between higher self-compassion and lower shame in brain injury [48]. Similarly, higher self-compassion was found to predict lower anxiety, depression, and higher resilience in those with epilepsy [49]. A systematic review into chronic health conditions and self-compassion-related interventions found that many of the therapies explored were associated with an improvement in outcomes such as anxiety, depression, and stress [50]. This not only suggests a relationship between self-compassion and psychological outcomes in populations with chronic health conditions, but also suggests that self-compassion can be practised and increased [37].

Whilst self-compassion has been explored in a variety of health conditions, there is less research into self-compassion with functional neurological conditions, including functional seizures. Self-compassion could be important for this population because of the stigma people with these conditions experience [51], for example those functional seizures have a higher risk of perceived stigma than people with epilepsy [52]. However, self-compassion can have a ‘buffer’ effect on the negative impact of stigma [53]. Self-compassion may do this by promoting the use of internal adaptive social, emotional, and cognitive mechanisms [54]. Similarly, self-compassion has also been associated with lower levels of shame [55] and self-criticism [56] in the general population.

The limited research that has been conducted in functional seizures suggests that self-compassion is related to better adjustment (measured by coping efficacy, quality of life, anxiety, and depression) in those with functional seizures [57]. Given that self-compassion could be argued to be an important construct in mental health and, in those with health conditions, further research is needed into the role of self-compassion in functional seizures.

Self-compassion may also be linked to experiential avoidance. Experiential avoidance could be argued to be a form of coping (choosing to cope by not engaging in unwanted thoughts, feelings, and sensations) and research has suggested that the coping strategies people with health conditions use can be influenced by self-compassion [44,58,59]. People may engage in experiential avoidance if they have difficulties with emotion regulation [60,61], and self-compassion has been related to emotion regulation, with emotion regulation being proposed to be a mechanism of change in the association between self-compassion and mental health [62]. Indeed, avoidance has been shown to negatively correlate with self-compassion, with people who have high compassion engaging in fewer avoidance strategies [63]. Furthermore, a mediation analysis found that general avoidance and behavioural activation were significant mediators of the relationship between self-compassion and depressive symptoms, in a non-clinical population [64].

In terms of experiential avoidance more specifically, one study found that mindfulness and self-compassion training increased self-compassion which was associated with a decrease in experiential avoidance which related to positive changes in psychological well-being [65]. Other studies have found self-compassion moderates the relationship between experiential avoidance and depressive symptoms [66], further suggesting that self-compassion could be a ‘buffer’ to psychological distress. Research suggests that when a person engages in less experiential avoidance, and instead is present with the uncomfortable thoughts, feelings, and sensations, they report less psychological distress [67]. It could be hypothesised that choosing to be in contact with these unwanted feelings is an act of self-compassion, as a person is fully experiencing their ‘suffering’ and then moving towards alleviating this. Considering these links, it could be important to look at the roles of self-compassion and experiential avoidance for those who experience functional seizures how this impacts psychological outcomes. We hypothesise that if a person is more self-compassionate, they would be more able to be present in their uncomfortable feelings and tolerate them rather than avoid and dismiss them through engaging in experiential avoidance, and that this in turn would lead to greater psychological well-being and fewer physical symptoms. Therefore, this study explored whether experiential avoidance mediated the relationship between self-compassion and psychological and physical outcomes for those who experience functional seizures. The outcomes measured were quality of life, depression, seizure severity and seizure frequency.

Specifically, the study addressed the following questions:

1. Is there a relationship between self-compassion and experiential avoidance in functional seizures?
2. Is there a relationship between self-compassion and outcomes in functional seizures?
3. Is there a relationship between experiential avoidance and outcomes in functional seizures?
4. Does experiential avoidance mediate the relationship between self-compassion and outcomes in functional seizures?

Method

Design

This study used a cross-sectional design involving quantitative measures, with data collected via an online survey and analysed using SPSS and the Hayes PROCESS tool [68]. Relationships between variables were explored via correlation and then a mediation model tested whether experiential avoidance mediated the relationship between self-compassion and outcomes. The outcomes measured were seizure severity, seizure frequency, quality of life and depression symptoms. The theoretical mediation model can be seen in Figure 2-1.

[Figure 2-1 around here]

Trauma was also originally selected as a variable for secondary analysis to explore whether there were any differences between participants who had experienced trauma and those who had not. Thus, participants also completed a trauma measure. However, due to most participants in the sample (90%) reporting that they had a trauma history, the results are reported in the sample characteristics, but not used for further analysis.

Participants

Participants were recruited internationally through various social media channels, support groups and charities (see below). The study survey was open from 1st February 2022 to 3rd January 2023. Prior to recruitment, empirical estimates from Fritz and Mackinnon [69] were taken to calculate the sample size needed for a small-medium or medium effect in both arms of the mediation model when using a bias-corrected bootstrap model. This suggested that for 80% power, 71 participants would be needed for a medium effect size in both arms and 148 participants for a small-medium effect in both arms. The analysis is based on 76 participants and therefore the study was powered to find medium effect sizes.

Inclusion criteria

Participants could take part if they:

- Had been diagnosed with functional seizures.
- Were 18 years old or older.
- Could complete the survey online (alone or with support)
- Had a good enough understanding of the English language to be able to comprehend the questionnaires.

Exclusion criteria

Participants were excluded if they:

- Had a diagnosis of epilepsy.

Procedure

FND Hope, a charity supporting those with FND, were involved throughout the study design process. A member of FND Hope UK was consulted on the selection of the measures used and was provided with a draft of the survey to ensure the questions were understandable, and the survey was not too burdensome. Feedback was taken from this consultation process and changes were made. Once ethical approval had been granted, the study was advertised on Twitter, Facebook and Reddit in appropriate groups which mainly consisted of FND and seizure support groups and FND Hope. As the study progressed, other charities and support groups were approached internationally with requests to advertise the study on their platforms.

People followed a link on the study advertisement to the survey webpage, which was hosted by Qualtrics. People were able to view the participant information sheet and consent page (see section 4: ethics), alongside contact details for the researcher and for sources of support (such as FND Hope). If participants gave their consent on the electronic form and confirmed that they met the eligibility criteria, they were then presented with the survey to complete.

Materials

The survey consisted of both validated measures and a demographic questionnaire, which was used to describe the sample and collect information on seizure frequency. The measures used can be seen in the ethics section of this thesis (section 4).

Predictor Variables

Self-compassion

Self-compassion was the predictor variable and it was measured using The Sussex-Oxford Compassion for the Self Scale (SOCS-S) [70]. This measure was selected due to it being aligned with Gilbert's [71] definition of self-compassion, which is how this study conceptualised self-compassion. This is a fairly new scale and has not yet been used in functional seizure research. However, it has been used in shame-related research [72], self-compassion in nursing [73] and in crisis line volunteers [74]. In all these studies, the SOCS-S was administered via an online questionnaire.

This measure is made up of 20 items using a Likert scale which ranges from one (not at all true) to five (always true). This measure also includes the subscales 'recognising suffering', 'understanding the universality of suffering', 'feeling for the person suffering', 'tolerating uncomfortable feelings' and 'acting or being motivated to act to alleviate suffering'. Higher scores on the total score or subscale scores indicate a higher level of self-compassion. This measure has been shown to have a good level of internal reliability for the total score (Cronbach's alpha = 0.75- 0.93) [70]. The lowest score possible on this measure is 20, and the highest is 100.

Mediator Variable

Experiential Avoidance

The mediator variable in this study was experiential avoidance. This was measured using the Multidimensional Experiential Avoidance Questionnaire (MEAQ) [75]. This measure has been used in functional seizure research previously [36]. This measure uses a Likert scale from one (strongly disagree) to 6 (strongly agree). The scale also includes subscales which are ‘behavioural avoidance’, ‘distress aversion’, ‘procrastination’, ‘distraction and suppression’, ‘repression and denial’ and ‘distress endurance’, alongside a total scale score. A higher score on this measure indicates more engagement in experiential avoidance. The highest total score possible on this measure is 317, and the lowest total score is 117. The total score measure has a good level of internal reliability (Cronbach’s alpha = 0.91-0.92) [75] and this alpha is seen in functional seizure groups also (0.91) [36].

Outcome Variables

Seizure Frequency

Seizure frequency was measured as part of the demographic questionnaire, and this consisted of one item asking how often participants experienced seizures. The seven options participants could select for this were ‘I am currently not experiencing functional seizures’, ‘I have functional seizures once or a few times a year but not every month’, ‘I typically have functional seizures 1-3 times a month’, ‘I typically have functionally seizures 4 or more times a month but not weekly’, ‘I typically have functional seizures 1-3 times a week’, ‘I have functional seizures 4 or more times per week but not daily’ and ‘I have functional seizures daily or almost every day’. A similar measure of seizure frequency has been used in functional seizure research previously [76].

Seizure Severity

Seizure severity was measured by using the Liverpool Seizure Severity Scale (LSSS-version 2) [77]. This measure has been used in functional seizure research previously [15,78]. The LSSS uses a Likert scale where participants rate the severity of their seizures and associated effects. The total score on this measure ranges from 0-100. Any participants who have not experienced seizures in the past 4 weeks automatically score 0 as a total score. A larger score in this measure is indicative of more severe seizures. This measure has good internal reliability (Cronbach’s alpha = 0.66-0.87) [79]. The functional seizure studies found utilising this measure did not report the alpha value for this measure in this population [15,78].

Mood

Mood was measured using the Depression, Anxiety and Stress Scale (DASS-21) [80], depression subscale items (seven items).This measure has been used within functional seizure research [81]. This measure uses a Likert scale where participants rate items from zero ‘did not apply to me at all’ to three ‘applied to me very much or most of the time’. The DASS-21 has good internal reliability, with the depression subscale having a Cronbach’s alpha of 0.91 [80]. A Cronbach’s alpha for the DASS-21 in functional seizure populations was searched for but could not be found at the time of writing. Total scores on the depression subscale of this measure can range from 0 to 42.

Quality-of-Life

A seizure-specific quality of life measure was selected to measure quality of life. This was the Quality of Life in Epilepsy Inventory (QOLIE-31) [82], which has been used in functional seizure research previously [22]. This 31-item questionnaire includes multiple Likert rating scales. Alongside the full quality of life score, there are also subscales for ‘seizure worry’, ‘overall quality of life’, ‘emotional well-being’, ‘energy/fatigue’, ‘cognitive’, ‘medication effects’ and ‘social function’. The total score on this measure can range between 0-100. The QOLIE-31 total score has good internal reliability (Cronbach’s alpha = 0.77-0.93) [82]. Avalos et al [22] did not report the Cronbach’s alpha for this measure in their functional seizure study.

Secondary Variable

Trauma

The Brief Trauma Questionnaire (BTQ) was used to identify the presence of historical trauma in participants. due to the emotional content, it was an optional measure at the end of the survey. The BTQ is derived from the Brief Trauma Interview [83]. At the time of writing this has not been used in functional seizure research but has been used in research into functional impairment [84]. The BTQ consists of 10 items in which participants respond ‘Yes’ or ‘No’ to whether they have experienced a certain type of traumatic event, whether they felt that they were in danger or could be injured during this event and whether they were seriously injured during this event.

Ethical Considerations

Ethical approval was granted for this study by Lancaster University Faculty of Health and Medicine Research Ethics Committee (reference: FHMREC21036) and further details regarding ethical approval can be seen in section 4. An application for an amendment was submitted and approved in May 2022, which enabled a wider advertising strategy for the study. The data gathered were stored in accordance with GDPR guidance and only consisted of electronic data.

Whilst there were no anticipated significant risks to participants, reasonable steps were taken to reduce the likelihood of distress following the study. It was made clear on the participant information sheet and consent form that participants could stop at any time.

However, due to the anonymity of the study, a person's data could not be identified and removed once they had commenced the survey.

Data Analysis

Fifty-nine potential participants viewed the information sheet and consent form but were unable to complete the survey due to not meeting the inclusion criteria as they had a diagnosis of epilepsy alongside functional seizures. There were 99 participants who consented to take part in the survey. Six participants only completed the demographic questionnaire and did not complete any further measures, so their data were removed from the analysis. In total, 93 participants completed some but not all measures and 76 participants completed all measures (excluding the trauma measure). The data from the 76 participants who completed all measures were included in the analysis.

The only measure with individual item missing data was the quality-of-life measure. Out of the 76 participants who completed the quality-of-life measure, 22 had 1-4 missing responses in total and their data were imputed via mean substitution.

Histograms, skewness, kurtosis, and tests of normality were used to first examine the data. Whilst the self-compassion, avoidance, seizure frequency and quality-of-life measures were normally distributed, the seizure severity and depression measures were not. Due to this, a non-parametric test, Spearman's rho, was selected for correlational analyses. A mediation analysis was then carried out using the Hayes Process Tool [68]. Bootstrapping analyses (10,000 samples) were used to test the mediation models. Avoidance was the mediator in this model, self-compassion was the independent variable, and the dependant variables were seizure frequency, depressive symptoms, seizure severity and quality-of-life. Prior to the mediation analysis, several regression analyses were run to check: outliers, multicollinearity, normality of residuals and homoscedasticity using scatterplots, q-q plots, and Cooks' distance. The outcome of this suggested that the residuals were normally distributed and homoscedastic for all variables.

Results

Participant Characteristics

Participant characteristics can be seen in detail in Table 2.1 The sample was 75% female. 17.1% male and 7.9% non-binary. The sample was made up of participants aged 18-69 (M= 35.87 SD= 12.25). Participants reported that their age at time of their diagnosis ranged between 15-65, with a mean diagnosis age of 32.75 (SD= 12.11). In terms of ethnicity, 43.4% of participants identified as ‘White British’ and 38.2% identified as ‘White Other’, which resulted in other ethnic backgrounds being under-represented in the sample. Similarly, most participants lived in the United Kingdom (53.9%) or the United States of America (26.3%). The remaining sample was made up of participants from Australia, various European countries, Canada, and one participant from Asia. Most of the sample either worked full-time (26.3%), part-time (14.5%), was a student (14.5%) or were unable to work (36.9%).

[Insert Table 2-1 here]

Participants were asked about any additional diagnoses they had received apart from functional seizures. 73.7% of participants reported having a diagnosis of Functional Neurological Disorder. This could suggest that most of this sample had more than one functional diagnosis, however, it is also possible that some participants had been given this label in relation to their functional seizures, rather than for additional functional symptoms. Further common diagnoses in this sample were depression (59.2%), anxiety (63.2%) and trauma (15.8%). Some participants also reported pain or fatigue related diagnoses, 7.9% of participants reported diagnosis of Autism and 9.2% reported diagnoses of a personality disorder. The sample varied in terms of the method used to diagnose their functional seizures, with MRI (71.1%), EEG and video (69.7%) and during a hospital stay (63.2%) being the most prevalent.

Descriptive Characteristics

[Insert Table 2-2 here]

As can be seen in table 2.2, participants had a mean score of 63.04 (SD= 12.67) on the self-compassion measure, where a higher score indicates a higher level of self-compassion. The Cronbach’s alpha for this measure was 0.92. Whilst there are no current studies using this measure with a functional seizure population the current sample is lower than a study of those with substance abuse disorder [85] and in a study of those working in ‘helping professions’ [86].

The mean score on the measure of avoidance was 218.57 (SD= 47.67), and a higher score in this measure indicates a higher level of experiential avoidance, and the non-clinical group used for the normative data on the measure scored a mean of 185.29 (SD= 39.95) [75]. The Cronbach’s alpha for this measure was calculated as 0.90. This score is similar to scores of avoidance in other functional seizure research using this measure [36] and is also similar to the psychiatric patient normative data reported in the development of the measure [75].

The Liverpool Seizure Severity Scale had a mean score of 45.99 (SD= 20.89), and a Cronbach’s alpha of 0.75. This average score of seizure severity is similar to that of other studies in functional seizures using this measure, such as in Green, Norman and Reuber [15], (M= 41.68, SD= 28.08). The range of scores on this measure was large (0-92.50), partly due to how the measure is scored.

A higher score on the QOLIE-31 indicates a higher level of quality-of-life and participants in this sample had a mean score of 39.17 (SD= 16.66) on this measure. This quality of life score is lower than some other functional seizure research (Avalos et al., 2020; Zaroff et al., 2004) The Cronbach's alpha of the quality-of-life measure was 0.91.

In the depression items of the DASS-21 that were administered, participants had a mean score of 33.79 (SD= 12.84), which falls in the 'extremely severe' category and the Cronbach's alpha was calculated as 0.93. A higher score on this measure suggests a higher level of depressive symptoms. In one functional seizure study, 9.59% of their functional seizure sample scored in the 'extremely severe' range [81], whereas in our sample 64.47% of participants scored within the 'extremely severe' range, suggesting that our sample had a higher level of depressive symptoms than other functional seizure samples.

In terms of seizure frequency, 22.6% of participants reported having daily seizures, 19.4% reported having seizures 1-3 times a week, 19.4% reported having seizures 1-3 times a month, 12.9% reported having seizures a few times per year, 11.8% reported having 4 or more seizures a month but not weekly, 10.8% reported having 4 or more seizures a week but not daily and 3.2% reported that they were not currently experiencing seizures. This single-item measure used Likert scoring 1-7, with 1 being 'I am currently not experiencing functional seizures' and 7 being 'I have functional seizures daily or almost every day'. The median score for seizure frequency was 5, 'I typically have functional seizures 1-3 times per week'. This level of seizure frequency is comparable to other functional seizure research using similar measures of seizure frequency [76]

Correlational Analysis

Non-parametric bivariate correlations can be seen in Table 2-3. All variables correlated in the expected direction at the p<0.01 level, apart from seizure frequency which was not correlated with self-compassion but significantly correlated with the other measures. Higher levels of self-compassion were strongly associated with lower levels of avoidance (r =

-0.61), moderately associated with reduced seizure severity (*r* = -0.37), strongly associated with a lower level of depressive symptoms (*r* = -0.56) and moderately associated with a higher quality-of-life (*r* = 0.43). Greater engagement in experiential avoidance was strongly linked to lower quality-of-life (*r* = -0.66), moderately related to a higher seizure severity (*r* = 0.40), weakly related to a higher seizure frequency (*r* = -0.21), and strongly associated with increased symptoms of depression (*r* = 0.74).

In terms of demographic characteristics, only weak or no associations were seen. Age had a significant weak negative correlation with scores on the DASS-D (*r* = -0.26). ANOVAs indicated that there was no significant difference between the gender groups (male, female, other) on any outcome variables.

[Insert Table 2-3 here]

Mediation Analyses

The mediation analyses consisted of four mediation models which investigated the effects of compassion via the indirect effect through experiential avoidance on psychological and physical health outcomes. Well-being was measured as quality-of-life using the QOLIE-31 (Model 1), depressive symptoms on the DASS-D (Model 2), seizure severity via the LSSS (Model 3) and seizure frequency (Model 4). A summary of the results can be seen in Table 2-4 and Figure 2-2. As part of a sensitivity analysis, a second set of models were also investigated as above but also controlling for gender and age.

[Table 2-4 here]

Model 1- Quality-of-life

The mediation analysis indicated that self-compassion was indirectly related to quality-of-life through experiential avoidance. Increased self-compassion was associated with lower engagement in experiential avoidance (a = -0.64, *p* < .001) and greater engagement in experiential avoidance was related to lower quality-of-life (b = -0.62, *p* < .001). There was a significant total effect between self-compassion and quality-of-life (c =0.55, *p* < .001) and this effect was no longer significant when the mediator, experiential avoidance was controlled for (c' = 0.04, *p* = 0.81). Experiential avoidance mediated the relationship between self-compassion and quality-of-life (ab = 0.52, 95%CI= 0.311, 0.77), as the confidence interval does not include zero. The completely standardised indirect effect was 0.39 (95%CI= 0.24 to 0.56)

Model 2- Depression Symptoms

The mediation analysis indicated that self-compassion was indirectly related to depression symptoms through its relationship with experiential avoidance. Increased self-compassion was related to lower engagement in experiential avoidance (a = -0.64, *p* < .001) and lower experiential avoidance was related to reduced symptoms of depression (b = 0.65, *p* < .001). There was a significant total effect between self-compassion and depressive symptoms (c = -0.55, *p* < .001) and this effect was no longer significant when the mediator, experiential avoidance, was controlled for (c' = -0.13, *p* = 0.20). Experiential avoidance mediated the relationship between self-compassion and depression symptoms (ab = -0.42, CI= -0.59, -0.26). The upper and lower confidence intervals of the completely standardised indirect effect were both below zero (ab= -0.41, CI= -0.57, -0.26), indicating that this indirect effect was significant.

Model 3- Seizure Severity

The mediation analysis indicated that self-compassion was indirectly related to seizure severity through its relationship with experiential avoidance. Increased self-compassion was related to lower engagement in experiential avoidance (a = -0.64, *p* < .001).

Higher experiential avoidance was related to increased seizure severity (b = 0.29, $p < .001$). There was a significant total effect between self-compassion and seizure severity (c = -0.57, $p < 0.05$) and this effect was no longer significant when controlling for experiential avoidance (c’ = -0.28, $p = 0.23$). Experiential avoidance mediated the relationship between self-compassion and seizure severity (ab = -0.30, CI= -0.60, -0.04). The upper and lower confidence intervals of the completely standardised indirect effect were both below zero (ab= -0.18, CI= -0.35, -0.02), indicating that this indirect effect was significant.

Model 4- Seizure Frequency

The analysis indicated that self-compassion was not indirectly related to seizure frequency through experiential avoidance. Increased self-compassion was related to a decrease in experiential avoidance (a = -0.64, $p < .001$). However, no significant relationship was found between experiential avoidance and seizure frequency (b = 0.19, $p = 0.21$). The total and direct effects between self-compassion and seizure frequency were also not significant (c = -0.03, $p = 0.11$), (c’ = -0.01, $p = 0.65$). The indirect effect between self-compassion and seizure frequency (ab = -0.02, 95%CI= -0.05, 0.01) was not significant as the confidence interval included zero.

Controlling for Gender and Age

Gender and age were controlled for in the mediation analyses. Model 1 and model 2 remained significant when controlling for age and gender. Model 3 (seizure severity) was still significant when controlling for gender only, however this was not observed when controlling for age as well. Model 4 remained non-significant.

Discussion

This study aimed to investigate the following within functional seizures; 1) the relationship between self-compassion and experiential avoidance 2) the relationship between self-compassion and outcomes 3) the relationship between experiential avoidance and outcomes and 4) whether experiential avoidance mediates the relationship between self-compassion and outcomes.

Expected relationships were observed for all variables except seizure frequency. Higher levels of self-compassion were associated with lower levels of experiential avoidance. Higher levels of self-compassion were also associated with lower levels of depression symptoms and seizure severity and higher levels of quality-of-life in those with functional seizures. Seizure frequency was not related to self-compassion but was significantly associated with the other variables. Higher levels of experiential avoidance were related to lower quality-of-life, higher levels of depressive symptoms, increased seizure severity and increase seizure frequency. Experiential avoidance was found to mediate the relationships between; self-compassion and quality-of-life (Model 1), self-compassion and depressive symptoms (Model 2) and self-compassion and seizure severity (Model 3) but not self-compassion and seizure frequency (Model 4). Model 3 became non-significant when controlling for age. It is not clear why this occurred; however, it could be an effect of including additional variables within the model which therefore reduces the likelihood of findings a significant effect and a larger sample may be needed to investigate further.

The correlational findings of this study support that of existing research with clinical samples. Firstly, self-compassion was associated with experiential avoidance. Whilst this relationship has not been investigated in a seizure population previously, this relationship has been observed in a sample with chronic pain [67]. It is possible that if someone is more self-compassionate, they are more able to engage with uncomfortable emotions and sensations, and less likely to engage in experiential avoidance.

The relationships seen between self-compassion and depression, or quality-of-life also replicate findings in existing literature in other health conditions [88]. These relationships are also seen more specifically in epilepsy and seizure research, with higher levels of self-compassion being associated with better psychological outcomes in epilepsy and functional seizures [49,57]. These two studies used different self-compassion, depression, and quality-of-life measures to this current study. Despite this, this study has corroborated their depression and self-compassion findings (which all reported a large effect size), further suggesting a role of self-compassion in depression. The study which investigated quality-of-life in epilepsy and functional seizures however reported that there was no significant relationship between self-compassion and quality-of-life in their functional seizure group, but that this relationship was found in their epilepsy and control groups [57]. This differs to our study which found a significant relationship between self-compassion and quality-of-life. This may be due to Clegg et al. [57] using a global quality-of-life measure rather than a condition-specific measure.

The significant relationship seen between self-compassion and seizure severity seen in this study is novel. This is also in contrast to an epilepsy study, which did not find a relationship between seizure severity and self-compassion, but did find relationships between seizure severity and depression [49].

The mediation analyses conducted in this study support existing literature but extend the findings to a functional seizure population. For example, behavioural avoidance has been previously seen to be a mediator in the relationship between self-compassion and depressive symptoms in a non-clinical population [64]. Experiential avoidance has also been seen to be a mediator in the relationship between self-compassion and anxiety, depression and well-being in another non-clinical sample [65]. The current study has demonstrated this mediating effect of experiential avoidance in a clinical sample, in which experiential avoidance has been found to be a particular difficulty [31].

The findings of this study suggest that being more self-compassionate is associated with less experiential avoidance, i.e., people can tolerate uncomfortable internal experiences. This has been seen previously in research, with self-compassion influencing the attitude people adopt and the feelings about themselves they experience in response to negative events. The researchers in this paper suggest that self-compassion may enable someone to be more accurate in their self-judgements whilst reflecting on a negative event, as a more self-compassionate person may be less self-critical and less defensive [89]. It could be that if a person is more self-compassionate, they adopt more ‘adaptive’ coping strategies, as seen in a meta-analysis [90], and this leads to less avoidance and thus better psychological outcomes.

In the current study, no significant relationship was found between self-compassion and seizure frequency, but seizure frequency was significantly related to the other variables. This differs to a piece of existing functional seizure research, which did not find a relationship between seizure frequency and quality-of-life [21]. Despite seizure frequency being a commonly measured outcome in functional seizure research, psychological variables are more consistently found to have a relationship with quality-of-life in this area of research. This discrepancy in the importance of seizure frequency has been discussed in recent research [91] and a recent systematic review of outcome measurements used in functional neurological disorder research highlighted the importance of standardising how seizure frequency was measured, including observing seizure severity and symptoms [92]. It is also possible that whilst a reduction in seizure frequency was not observed with an increase in self-compassion, there could be a reduction in seizure worry, as someone could become more accepting of their difficulties despite the difficulties remaining. Further research could explore the seizure worry subscale of the quality-of-life measure used in this study and its relationship with self-compassion.

The sample in this study appeared broadly similar to previous research of those with functional seizures. The sample was 75% female and larger-scale studies had a similar percentage (72%), congruent with the finding this diagnosis is more prevalent in females than males [12]. However, the sample also contained participants who identified as non-binary (7.9%) and this does not appear to have been previously identified, although it is unclear if previous research has presumed gender is binary. The mean age of participants and mean age of diagnosis in our sample is similar to larger sample randomised control trial research in functional seizures [12].

The current sample reported varied additional diagnoses, with the most common being depression, anxiety, trauma, pain, autism, and personality disorders. Associations between functional seizures and anxiety, depression or trauma have been identified in previous research [93] and a systematic review has suggested that there is an increased risk of personality disorder in those with functional seizures [94]. A recent paper also found a high level of autistic traits in their functional neurological disorder sample [95]. However, research regarding personality traits in functional seizures varies, with some reporting traits of ‘borderline or depressive personality disorders’ being more prevalent in functional seizures than epilepsy [13] and others not finding a specific personality profile when comparing functional seizure and epilepsy groups [14,96]. The level of depression symptoms in this sample was particularly high compared to previous functional seizure research [81], which could possibly be due to the high levels of trauma reported in this sample.

Clinical implications

The findings of this study suggest the importance of self-compassion and experiential avoidance in terms of well-being in those with functional seizures. Compassion Focused Therapy (CFT) is one therapeutic approach which draws on these concepts as it aims to increase self-compassion, and through this process improve psychological well-being [97]. A meta-analysis of CFT reported that compassion-based interventions resulted in a ‘moderate and significant’ increase in self-compassion and indicators of psychological well-being across a range of samples [98]. This has also been seen within health conditions, with CFT leading to greater acceptance of a condition, reduced anxiety and depression, reduced isolation and increased emotion regulation [99]. CFT research in functional conditions is limited, but one case study of CFT in functional movement disorder reported promising results, with a decrease in the psychological impact of the condition seen post-intervention [100]. This, alongside the results of our study suggest the importance of investigating and developing compassion-cultivating interventions for those with functional seizures.

Experiential avoidance is a key process targeted within the Acceptance and Commitment Therapy (ACT) model and is associated with cognitive fusion, another mechanism within ACT [101]. Cognitive fusion is described as regulating one’s behaviour through rigid cognitions including self-evaluative thoughts [102] and can have a bi-directional relationship with experiential avoidance [103] as avoiding unwanted experiences could reinforce cognitions. Thus, an awareness of a client’s cognitions as well as their engagement in experiential avoidance may be useful. There is also research around the inclusion of self-compassion in ACT and how engaging in ACT processes such as acceptance and committed action are self-compassionate due to the practice of relating to oneself more flexibly and empathetically within ACT [104,105]. Furthermore, links between self-compassion and experiential avoidance and the importance of these processes have been explored in mindfulness and self-compassion training research [65].

Research into psychological therapies to reduce functional seizures is in its infancy, although some studies have shown promise. A meta-analysis of psychological interventions in functional seizures found that 47% of people reported that they were seizure-free at the end of a psychological intervention. However, the importance of being flexible within an intervention was highlighted due to the diversity of experiences in functional seizures and the mechanisms not being well-understood [106], and thus further work in this area is needed.

A recent functional seizure randomised controlled trial of Cognitive Behavioural Therapy found that the intervention group reported less functional impairment and higher ‘clinical improvement’ scores than the standardised medical care group at 12-month follow-up [91]. However, there was no significant difference between the groups in psychological distress or seizure frequency at 12-month follow-up. The researchers note that this may be due to seizure frequency reducing over time as the disorder continues, or that standardised medical care could be an intervention in itself [91]. This may suggest that the content or model of the intervention is not as important as the presence of the intervention itself. Future research could assess the use of other interventions in functional seizures.

Limitations

This study is a cross-sectional mediation study and so has limitations in that whilst correlational relationships are identified, these are not causal. Additionally, due to the cross-sectional nature of this study, the relationships between variables could be bi-directional – and thus experiential avoidance may also lead to lower self-compassion, instead of the models presented currently. Additional variables could also play a role in the relationships between the variables in this model. For example, research has found psychological flexibility to be a significant mediator of the relationship between self-compassion and psychological distress [105]. Furthermore, there is a body of research suggesting interactions between self-compassion and mindfulness [107]. Experiential avoidance has also been seen to mediate the relationship between mindfulness and anxiety in a non-clinical sample [108]. Additionally, within functional seizures higher experiential avoidance has been associated with lower mindfulness, and mindfulness predicts somatization which can impact seizure frequency [76]. Therefore, it may be that being self-compassionate allows one to be more mindful, or engaging in more mindfulness behaviours decreases experiential avoidance. It is also possible that to be self-compassionate one needs to be mindful as one needs to be aware of their current experience to be compassionate towards themselves within the experience [109]. It could be interesting to explore these various interactions using more complex models. Self-compassion has also been seen to play a moderating role in relationships such as between experiential avoidance and depression [66] and so this moderating role of self-compassion may warrant further examination in clinical populations, including functional seizures.

As the study was carried out using an online survey there is the possibility that the participants recruited were similar in terms of how well the participants were in terms of their physical or mental health (in that they were able to engage with the survey). Additionally, perhaps people who are more actively involved in charity or social media community group pages could be more likely to take part.

The wide recruitment strategy enabled participation from a range of countries. However, our sample was mainly western in terms of both ethnicity and location, which impacts the generalisability of the findings, particularly because the concepts of self-compassion and experiential avoidance could vary across cultures [110–112] and the manifestation of functional seizure symptomology can be difference across cultures [113]. The study was limited in terms of its relatively small sample size which again impacts generalisability. The study was only powered to find medium effect sizes, but these effects were found for all expected relationships, except seizure frequency. It appears therefore that the effects for seizure frequency are thus smaller than for the other outcomes although these might have been detectable with a larger sample.

However, there are limitations in relation to the seizure frequency measure used. The seizure frequency measure was given alongside the demographic measure at the start of the survey and was based on a seizure frequency measure previously used in functional seizure research [76]. The seizure frequency measure only had 7 categories which varied in size and therefore is not a true linear scale. This is also not a validated measure of seizure frequency. As discussed previously, existing research varies in how seizure frequency is measured and research groups have been tasked with standardising how this outcome is measured, as well as discussing whether outcomes such as seizure severity are more valuable in functional seizure research [92]. It is also possible that it may be less helpful to target or measure seizure-related variables and more appropriate to focus on aspects of psychological well-being, as perhaps the focus should be on ‘living well’ with the condition, rather than reducing the physical symptoms. This would have clinical implications for therapies such as ACT, as the goals of this therapy could be around reducing distress associated with seizures and connecting to one’s values, rather than reducing the seizures themselves. Furthermore, this would also suggest the need to explore psychological variables, rather than solely seizure-related outcomes, when assessing the effectiveness of interventions in people with functional seizures.

Future Research

The experiential avoidance measure used in this study has subscales for different types of experiential avoidance: behavioural avoidance, distress aversion, procrastination, distraction and suppression, repression and denial, and distress endurance. It would be interesting for future research to consider whether different types of experiential avoidance are associated with different levels of self-compassion and outcomes. This could enable exploration of more complex models of interaction between aspects of experiential avoidance and self-compassion. In addition, prior functional seizure research has reported significant relationships between anxiety and experiential avoidance [36], and so our mediation study could be replicated with anxiety as an outcome.

Engaging in self-compassionate behaviour can be challenging for some individuals and research is also beginning to investigate a fear of self-compassion. Fear of self-compassion has been linked with psychological outcomes such as depression and shame [114]. It could be interesting to see whether those with a higher fear of compassion or shame engage in more experiential avoidance, particularly due to the presence of shame in those with functional seizures [115].

Future research could also include a sample of people with both epilepsy and functional seizure diagnoses. Given the differences noted previously in psychological characteristics of those with epilepsy and those with functional seizures, it would be interesting to explore the well-being of those who hold both diagnoses.

Conclusions

This study aimed to explore the relationships between self-compassion, experiential avoidance, and psychological and physical outcomes in those who have a diagnosis of functional seizures. Increased self-compassion and decreased experiential avoidance were associated with increased quality-of-life scores and decreased symptoms of depression and seizure severity. Experiential avoidance significantly mediated the relationship between self-compassion and quality-of-life, depression symptoms and seizure severity. This study highlights the importance of psychological mechanisms such as self-compassion and experiential avoidance for wellbeing for those living with functional seizures.

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Table 2-1

Sample Demographics

Table 2-1

Sample demographics (N= 76)

	n	%	Mean	Standard Deviation	Range
Age			35.87	12.25	18-69
Age at diagnosis			32.75	12.11	15-65
Gender					
Male	13	17.1			
Female	57	75.0			
Non-Binary	6	7.9			
Ethnicity					
White British	33	43.4			
White Other	29	38.2			
Asian or Asian British	2	2.6			
Black, Black British, Caribbean, or African	2	2.6			
Mixed	2	2.6			
Other	8	10.5			
Country of residence					
United Kingdom	41	53.9			
United States of America	20	26.3			
Australia	5	6.6			
Canada	3	3.9			
Belgium	3	3.9			
Lithuania	1	1.3			
India	1	1.3			
France	1	1.3			
Sweden	1	1.3			
Work Status					
Employed full time	20	26.3			
Employed part time	11	14.5			
Student/Apprenticeship	11	14.5			
Full-time unpaid carer	1	1.3			
Signed off work- sick	8	10.5			
Retired	2	2.6			
Unable to work- receiving disability benefits	18	23.7			
Unable to work- not receiving disability benefits	10	13.2			

Unemployed- not looking for work	0	0
Maternity/Paternity leave	1	1.3
Other	1	1.3
Additional Diagnoses		
FND	56	73.7
Depression	45	59.2
Anxiety	48	63.2
Trauma (PTSD/CPTSD)	12	15.8
Autism Spectrum Disorders	6	7.9
Chronic Fatigue Syndrome	1	1.3
Fibromyalgia	5	6.6
Chronic Pain	4	5.3
Migraine	3	3.9
Personality Disorder	7	9.2
ADHD	4	5.3
Bipolar Disorder or Hypomania	3	3.9
Dissociative Identity Disorder or Depersonalisation	3	3.9
Cardiovascular difficulties	1	1.3
Osteoarthritis/Osteoporosis	3	3.9
Cancer	1	1.3
Non-cancerous tumour	1	1.3
Irritable Bowel Syndrome	1	1.3
Obsessive Compulsive Disorder	2	2.6
Sleep difficulties	2	2.6
Speech difficulties/Tourette's Syndrome	2	2.6
Ehlers's-*Danlos Syndrome*	1	1.3
None	4	5.3
FS Diagnosis Method		
MRI	54	71.1
EEG and video	53	69.7
By General Practitioner/ Family Doctor	10	13.2
In hospital	48	63.2
Other	17	22.4
Seizure Frequency		
Not currently experiencing functional seizures	3	3.9
Once or a few times a year but not every month	8	10.5
1-3 times a month	13	17.1
4 or more times a month but not weekly	10	13.2
1-3 times a week	14	18.4

4 or more times a week but not daily	10	13.2
Daily or almost every day	18	23.7

Note: The questions regarding work status, additional diagnoses and diagnosis method allowed participants to select multiple answers and provide answers qualitatively. Therefore, the total percentage seen in the table can be larger than 100 due to participants selecting multiple options. FND- Functional Neurological Disorder, PTSD- Post-Traumatic Stress Disorder, CPTSD- Complex Post-Traumatic Stress Disorder, ADHD- Attention Deficit Hyperactivity Disorder, MRI- Magnetic Resonance Imaging, EEG- Electroencephalography.

Table 2-2

Means, Standard Deviations and Cronbach's alpha of measures

Table 2-2

Means, Standard Deviations and Cronbach's alpha of measures used (N=76)

Measure	N completed	M (SD)	Score range	Cronbach's alpha
SOCS-S	76	63.04 (12.67)	30-88	0.92
MEAQ	76	218.57 (47.67)	89-296	0.90
LSSS	76	45.99 (20.89)	0-92.50	0.75
QOLIE-31	76	39.17 (16.66)	9.30-78.75	0.91
DASS-D	76	33.79 (12.84)	14-56	0.93
BTQ*	70	63 Yes/ 7 No	N/A	N/A

Note: SOCS-S Sussex Oxford Compassion for Self-Scale; MEAQ Multidimensional Experiential Avoidance Questionnaire; LSSS Liverpool Seizure Severity Scale; QOLIE-31 Quality-of-Life in Epilepsy Questionnaire; DASS-D Depression Anxiety Stress Scale-Depression subscale; BTQ Brief Trauma Questionnaire. Higher scores relate to higher levels of the variable being measured. *The BTQ is used to describe the sample and is not used in analysis. 63 participants reported having a history of trauma, 7 reported that they did not.

Table 2-3

Non-parametric correlations

Table 2-3

Bivariate correlations between variables using a non-parametric test (N=76)

	Age	Seizure Freq	SOCS-S	MEAQ	LSSS	QOLIE-31	DASS-D
Age	1	-0.119	-0.056	-0.194	-0.142	0.153	-0.261*
Seizure Freq		1	-0.210	0.248*	0.316**	-0.428**	0.332**
SOCS-S			1	-0.608**	-0.373**	0.430**	-0.564**
MEAQ				1	0.401**	-0.664**	0.744**
LSSS					1	-0.521**	0.435**
QOLIE-31						1	-0.768**
DASS-D							1

Note: SOCS-S Sussex Oxford Compassion for Self-Scale; MEAQ Multidimensional Experiential Avoidance Questionnaire; LSSS Liverpool Seizure Severity Scale; QOLIE-31 Quality-of-Life in Epilepsy Questionnaire; DASS-D Depression Anxiety Stress Scale-Depression subscale.

** p<0.01

*p<0.05

Table 2-4

Mediation Analyses

Table 2-4

Mediation Analyses

	Model 1 X= self-compassion M= experiential avoidance Y= quality-of-life	Model 2 X= self-compassion M= experiential avoidance Y= depressive symptoms	Model 3 X= self-compassion M= experiential avoidance Y= seizure severity	Model 4 X= self-compassion M= experiential avoidance Y= seizure frequency
a	-0.638***	-0.638***	-0.638***	-0.638***
b	-0.623***	0.651***	0.288***	0.185
c'	0.036	-0.134	-0.275	-0.009
c	0.552***	-0.549***	-0.573**	-0.027
ab	0.516^	-0.415^	-0.299^	-0.017
ab CI	0.311, 0.770	-0.592, -0.263	-0.603, -0.036	-0.045, 0.008
CSIE	0.392^	-0.410^	-0.181^	-0.116
CSIE CI	0.242, 0.567	-0.573, -0.259	-0.354, -0.023	-0.298, 0.061

*$p < 0.05$, **$p < 0.01$, ***$p < 0.001$

^ Significant indirect effect with 95% CI

Note: X= predictor, M= mediator, Y= outcome, c’ = direct effect of X on Y controlling for M, c = total effect of X on Y, ab= indirect (mediated) effect, CI= confidence interval, CSIE= completely standardised indirect effect.

Figure 2-1

Theoretical model

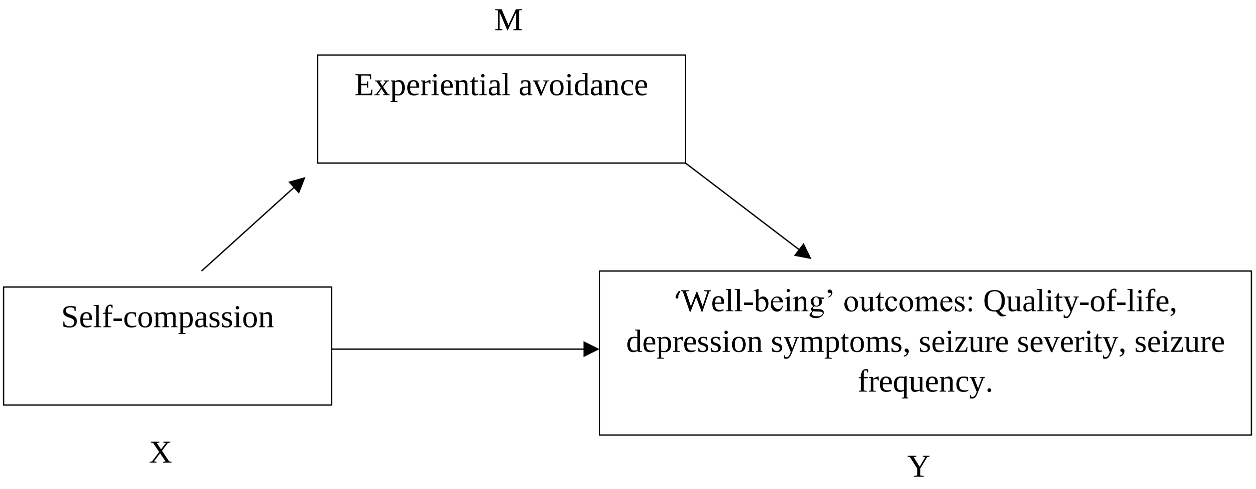
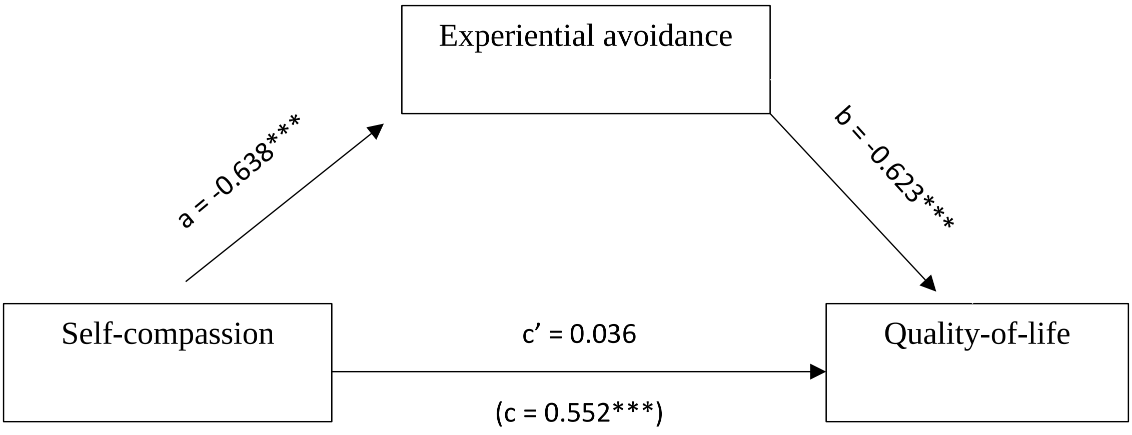


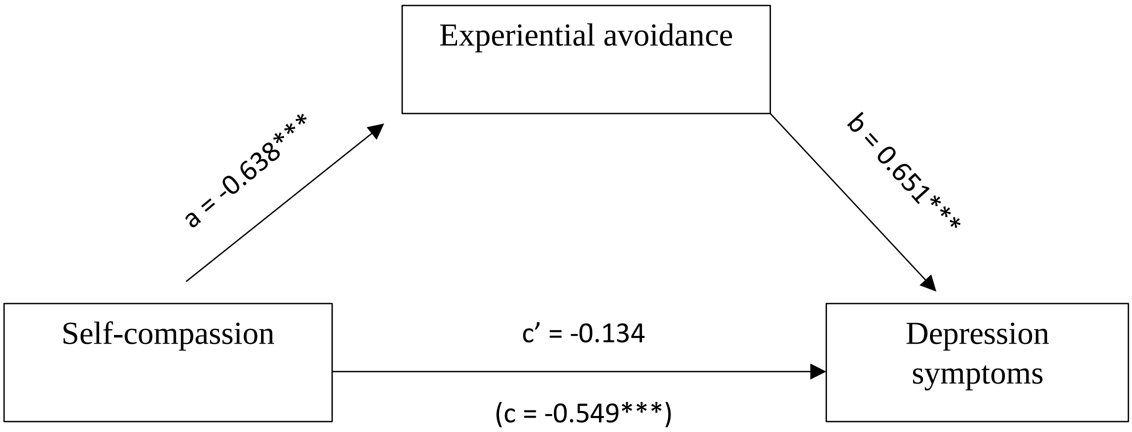
Figure 2-2

Mediation models

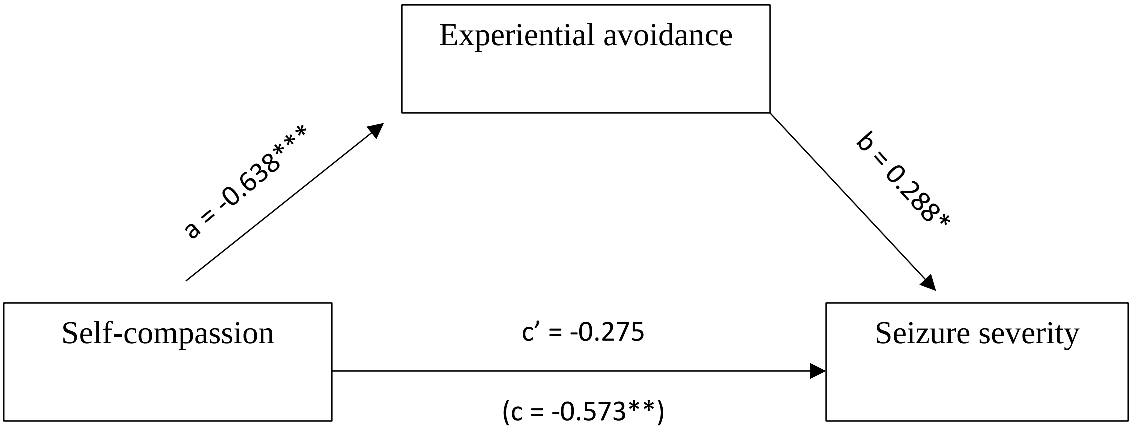
Model 1



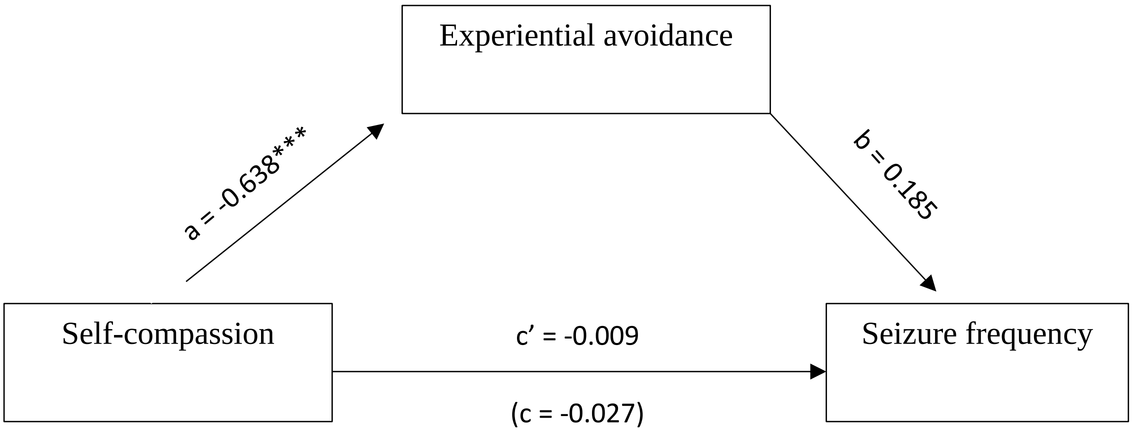
Model 2



Model 3



Model 4



Note: *p < 0.05, **p < 0.01, ***p < 0.001

Appendix 2

Author Guidelines for Epilepsy & Behavior

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Section 3: Critical Appraisal

Word count (excluding references, appendices, and tables): 3,435.

Megan Hawkes
Lancaster University Doctorate in Clinical Psychology
May 2023

All correspondence should be sent to:

Megan Hawkes
Doctorate in Clinical Psychology
Health Innovation One
Lancaster University
LA1 4AT
Email: m.hawkes@lancaster.ac.uk

This critical appraisal will first provide an overview of the findings of the literature review and empirical paper. Any challenges and decision points which arose during the thesis process will then be explored, alongside potential solutions and ideas for future research.

Summary of Research

Scoping review

The scoping review aimed to ‘map out’ existing literature regarding the role of self-compassion in neurological conditions. This review had a particular focus on intervention studies and explored: how self-compassion was measured, the methodology used in these studies, the types of interventions investigated, the outcomes that have been targeted and any mechanisms for change that have been suggested. This review was selected due to the wealth of research suggesting that high levels of self-compassion are associated with better psychological and physical outcomes for those with physical health conditions [1,2]. Despite there being existing reviews on the role of self-compassion in physical health conditions [2,3], these reviews did not focus on neurological conditions, and people with neurological conditions may face additional specific challenges such as cognitive impairments, stigma, and chronic fatigue [4–6].

Seventeen papers were included in this review, seven of which were randomised control trails (RCTs), eight were single group pre- and post-test design, and two were case studies. The interventions could be split into two types: compassion-focused, such as Compassion Focused Therapy (CFT) and mindfulness-based, such as Mindfulness Based Stress Reduction (MBSR).

Compassion-focused RCTs did not consistently measure self-compassion, which made it difficult to ascertain whether any changes to psychological or physical outcomes were due to an increase in self-compassion, or due to another internal process. Additionally, some studies were unclear in their methodology and/or had a small sample size, reducing the quality of the research and further limiting any conclusions that can be drawn.

The review included a range of conditions, but multiple sclerosis was the most common, particularly within the mindfulness-related intervention studies. Within the compassion-focused studies, brain injuries were the most frequently explored condition. The review explored how studies had adapted their intervention from a manualised approach, as well as any adaptations made for the neurological condition they were working with (such as adaptations for cognitive impairment or fatigue). Some studies in this review suggested that self-compassion takes time to develop, and so changes in self-compassion may not be seen if an intervention is too short or if self-compassion was measured immediately after an intervention with no follow-up.

In conclusion, the review highlighted that whilst self-compassion is investigated (either as an outcome or as a change mechanism) in neurological conditions, it is not always explicitly measured. More robust research is needed to explore the development of self-compassion and how this might relate to other processes such as mindfulness. Future research also needs to consider overtly stating the content of their intervention (and any adaptations) as this was not always clear. The conditions explored in this area of research are also limited, and so future research could consider less frequently investigated neurological conditions, such as functional neurological conditions.

Empirical paper

This study explored the role of self-compassion and experiential avoidance in functional seizures (FS). High levels of self-compassion have been associated with beneficial outcomes such as reduced distress and increased aspects of positive well-being in non-clinical and clinical populations, including those with long-term health conditions [7–9]. However, there is less research exploring the role self-compassion may play in less ‘well understood’ conditions. Research has suggested that people with FS are likely to engage in experiential avoidance [10] and that experiential avoidance has a negative relationship with self-compassion [11,12]. This study used a mediation model to explore these relationships in FS.

Within the mediation model self-compassion was the predictor, experiential avoidance was the mediator and the outcomes measured were quality-of-life, depression symptoms, seizure severity and seizure frequency. Trauma was also measured due to the reported prevalence of trauma in this population [13,14], however due to 90% of our sample reporting an experience of trauma, this was excluded from the analysis. Seventy-six participants completed all questionnaires and so the data from these participants was included in the analysis. In terms of demographics, the sample was similar to those seen in previous FS research [15].

The results showed that an increase in self-compassion was associated with a decrease in experiential avoidance, depression symptoms, seizure severity and an increase in quality-of-life. Seizure frequency was not associated with self-compassion but was associated with the other measures, including experiential avoidance. A decrease in experiential avoidance was related to an increase in quality-of-life and a decrease in depressive symptoms and seizure severity. Experiential avoidance significantly mediated the relationship between self-compassion and quality-of-life, self-compassion and depression symptoms, and self-compassion and seizure severity. The findings fit our hypothesis, except for the absence of a significant relationship between self-compassion and seizure frequency.

The findings of the correlational and mediation analyses in this study support existing literature [11,16–19]. The results of this study suggest that being more self-compassionate could lead to being more able to engage with uncomfortable internal feelings, which could result in better psychological and seizure-specific outcomes. This could also suggest the importance of exploring the use of self-compassion promoting interventions in FS.

Strengths, limitations, and opportunities for improvement

Scoping review

The limitations of the scoping review are acknowledged within the paper but in brief, this type of review limits the ability to explore the effectiveness of the interventions. However, the use of a scoping review allowed me to 'map out' the literature.

It could be useful for future reviews to explore the experiences of shame or self-criticism within neurological conditions and the relation of these factors to self-compassion, or compassion-focused interventions. People with neurological conditions such as brain injury and Parkinson's disease experience high levels of shame or self-criticism [20,21], and there is wider research demonstrating links between these concepts and self-compassion [22,23]. Furthermore, shame and self-criticism are sometimes targeted within compassion-based interventions such as CFT [24,25] and are reportedly effective at decreasing feelings of shame or self-criticism [26,27], so it would be helpful to see if this effectiveness is also present in those with various neurological conditions. Similarly, the effect of shame and stigma has been observed within FS, with some suggestion that these concepts can predispose someone to (or perpetuate) FS [28,29]. Therefore, it could have been useful to look at shame and stigma in my empirical paper also, and this could be an area for future research. Additionally, the compassion-based interventions in my review did not increase self-compassion (with one exception), it could be that instead these interventions impacted another process (such as self-criticism, mindfulness, or psychological flexibility for example) which affected outcomes. On the other hand, as explored within the review paper, it could be that there was a barrier to the development of self-compassion, such as fear of compassion, in the samples seen in the papers within the review or that the intervention used was not long enough to observe a change in self-compassion. There is a need for future research exploring the development of self-compassion longitudinally and to investigate the interaction of self-compassion and other processes using more complex models.

Empirical paper

An overview of the strengths and limitations of the empirical study are provided within the paper; therefore, this section will focus on the most pertinent points. Firstly, the study excluded people with epilepsy diagnoses. This decision was made due to the focus of the paper being on potential important mechanisms (self-compassion and experiential avoidance) in FS. Existing research has suggested differences between those with epilepsy and those with FS, in terms of levels of depression or anxiety [30,31], quality-of-life [32,33] and trauma experience [14]. Therefore, including those with epilepsy would make it more difficult to attribute any difficulties with self-compassion, experiential avoidance, or outcomes to the experience of FS, rather than the experience of epilepsy. However, by making this decision we excluded 59 potential participants (based on the data we have on who completed the consent form). The proportion of people who have epilepsy and also a FS diagnosis varies between studies, with one reporting that 9.4% of their 32 participant sample held both diagnoses [34] and a review reporting the prevalence of FS in epilepsy to be 12% and epilepsy in FS to be around 22% [35]. There has been some suggestion that a diagnosis of epilepsy may be one risk factor for experiencing FS, both due to neurobiology and the model learning of a seizure [36,37].

It would be interesting for future research to explore the experiences of those who hold both diagnoses, through qualitative and quantitative research. An example of this is one paper comparing the psychological profile of those with an epilepsy diagnosis to those with a FS diagnosis and those who hold both diagnoses. This paper suggested that the clinical symptoms displayed in each group were different, but that the FS group had similar personality profiles to that of the FS and epilepsy group [38]. Another study suggested that the prevalence of posttraumatic stress disorder and dissociation was higher in a ‘pure’ FS group compared to a dual-diagnosis FS and epilepsy group [39]. Therefore, it could be helpful to explore whether those with FS and epilepsy engage in similar internal processes (such as self-compassion or experiential avoidance) to those with just a FS diagnosis. Whilst comparisons of self-compassion between FS and epilepsy groups has been done previously [17], this did not include those who hold both diagnoses.

Secondly, the measures used within the study have limitations and alternative measures could be used in future research. As discussed, the seizure frequency measure used was taken from a previous FS study [40] but was not a validated measure and was not continuous due to it only having seven response categories. There is a discrepancy in measuring seizure frequency seen in existing research [41]. It could be helpful for future FS studies to measure seizure frequency consistently using the same tool, which would allow for comparison between studies. However, it could be that seizure severity is a more useful indicator of condition-related physical health or severity [41]. Additionally, seizure frequency is not always related to quality-of-life in FS, but this relationship is found in epilepsy, perhaps due to the unpredictability of seizures in FS [42].

The seizure severity measure used in the empirical paper was the Liverpool Seizure Severity questionnaire [43], which has been used in FS research previously [31]. Due to the scoring instructions of the severity measure, if a participant had not experienced a seizure in the past four weeks, they scored 0 overall on the measure. This could mean that the measure did not accurately capture a person’s average or typical seizure severity, particularly if the person happened to experience less severe seizures in the past month than they usually would. While this measure has been used within functional seizure research, it is not clear from searching whether this has been validated for use within functional seizures.

The Quality-of-Life in Epilepsy questionnaire (QOLIE) is the most commonly used quality-of-life measure in FS, however it has only been validated for use within epilepsy, and the validity of this measure has not been assessed in FS [42]. Additionally, there were some items which appeared epilepsy specific (such as medication effects), which could have led to confusion when participants were completing the measure. Furthermore, there is potential for overlap between the QOLIE and the seizure severity measure, particularly with the items relating to cognition or physical health in the QOLIE, however the seizure severity measure is more seizure symptom specific. Additionally, attrition was seen throughout the study but particularly when participants were completing the experiential avoidance measure, perhaps due to the length of the measure and so future studies may benefit from using shorter measures. There may also be a need for a FS specific quality-of-life measure to be developed.

Finally, there are other variables the empirical paper could have explored. For example, anxiety could have been investigated as an outcome instead of depression, due to difficulties with anxiety seen in FS [30] and relationships seen between anxiety and avoidance in FS [44]. It could have been useful to explore a fear of compassion in both the empirical and review papers, as it may be that this is a barrier to developing compassion [45] and a fear of compassion has been observed in other neurological samples (such as brain injury) [46,47]. As explored in the empirical discussion, more complex models also could have been investigated, particularly if we had a larger sample, such as the moderating role of self-compassion, or a mediating role of other factors such as mindfulness. Various examples of these models can be seen in existing research in health condition samples [48,49], but not in FS. Interestingly, the mediation model we used was not significant when tested the other way around, with experiential avoidance as the predictor and self-compassion as the mediator, as the confidence intervals included 0.

Decision-making and process challenges

Scoping review

The scoping review initially set out to explore the role of self-compassion in neurological conditions, however as the review progressed the decision was made to alter the review to be specifically about intervention studies within this question, and for a further review to consider observational studies. This decision was made after the search was conducted and during the synthesis of the papers which met the inclusion criteria. It became apparent that the 37 papers could not be adequately covered within one review to the depth that I felt was needed, particularly because the intervention and observational papers included a variety of key messages and themes. Whilst I still feel that splitting this review into two reviews was the right decision in terms of meeting the scoping reviews aims of mapping the literature, it would have been helpful for this decision to be made at an earlier point in the process. This would have minimised the duplication of work that occurred and would have been timesaving. On reflection, I feel that a scoping review methodology was the correct one to use, rather than a type of systematic review, due to the relative paucity of research in any one condition and the evidence base still developing, meaning that summarising what research currently exists felt more relevant than assessing the quality of the evidence.

As briefly explored in the review, the constructs of mindfulness and self-compassion could overlap, or one could lead to the development of the other. There is a wealth of research into the relationships between mindfulness and self-compassion, generally suggesting that one increases the other and that some components of each are similar (such as non-judgement) [e.g. 50,51]. There is a suggestion that mindfulness and compassion cannot exist without the other, as a person needs to be mindful and aware of their internal experiences to be compassionate towards themselves, with the opposite also being true [52]. Furthermore, it could be that mindfulness aids us in regulating negative feelings whereas compassion fosters positive emotions [52]. Due to the focus of this review being on self-compassion, the decision was made to only include mindfulness papers which measured self-compassion or reported self-compassion as a theme in their qualitative findings. However, this may have led to an over emphasis of the importance of self-compassion when mindfulness may be equally if not more important (or more widely researched). There are some existing reviews regarding mindfulness interventions and neurological conditions [53,54], however future reviews could explore mindfulness in neurological conditions within non-intervention studies, or mindfulness within functional conditions.

Additionally, as discussed in the empirical paper, self-compassion is beginning to be investigated within other models such as Acceptance and Commitment Therapy (ACT) [55,56]. Whilst there may be overlap between (and relationships between) self-compassion and mindfulness, there may also be relationships between self-compassion and other aspects of ACT, such as psychological inflexibility. This has been seen in previous non-clinical research, with higher levels of self-compassion being associated with lower psychological inflexibility or higher psychological flexibility [57,58]. Research also suggests that self-compassion and psychological inflexibility together are more strongly related to psychological health than a single score of mindfulness [58]. Psychological inflexibility is also commonly found in FS and can be measured in terms of engagement in more experiential avoidance and cognitive fusion [40]. There is a suggestion that in FS higher experiential avoidance and cognitive fusion is related to lower mindfulness, which may lead to increased somatization and more frequent seizures [40]. Therefore, it could be helpful for future reviews to explore how psychological inflexibility (and its variables) have been measured within neurological conditions, and for future empirical studies to consider the potential roles of psychological inflexibility and self-compassion in FS.

Empirical paper

As previously discussed, the data from the trauma questionnaire was omitted from analysis due to most of our sample having experienced some form of trauma. Our initial aim was to use this information to make comparisons between a trauma-experienced and non-trauma-experienced group. On reflection, I wonder whether it would have been more ethical to omit the trauma questionnaire prior to the study, or perhaps to use a more specific trauma measure and then make comparisons between different types of traumas, trauma symptoms, or when the trauma occurred in someone's life. This could have potentially given us more information on whether self-compassion acts as a 'protective' factor in the development of trauma symptomology in FS, as seen in other clinical samples [59] or whether self-compassion was related to the specific trauma someone experiences [60]. Whilst an additional information sheet and consent form was given prior to the optional trauma measure at the end of the survey, the measure could have still caused some distress. If I were to conduct the empirical study again, I would remove the trauma measure or include a measure that provided us with more detailed data.

Possibly the most difficult decision to make in the process of the empirical study was the selection of the self-compassion measure. The SCS [61] has been used widely and frequently in self-compassion research [62], including within FS research previously [17]. However, there have been recent criticisms of the scale. An example of this is that the total SCS score is often used in papers despite this including both positive and negative items, which means that a distinction between self-compassion and self-criticism or other psychopathology cannot be clearly made [63]. The 'un-compassionate' items in the measure could also relate to a mental health difficulty, rather than a lack of the protective trait of self-compassion [62]. Despite this, Neff [64] claims that the SCS total score should not be split into compassionate and uncompassionate responding, instead stating that they exist in a ‘bipolar continuum’.

A systematic review of the definition of self-compassion summarised self-compassion as involving five key elements [65] and from this the Sussex-Oxford Compassion Scale (SOCS) [66] was developed, including the compassion towards self-scale which we used within our study. The SOCS has been demonstrated to be a valid and internally consistent measure of compassion towards self and others, and has started to be translated into various languages [67–69]. The SOCS was selected due to an awareness of the recent criticisms of the SCS, the recent development of the SOCS, and wanting to contribute to the evidence base utilising this measure, rather than continuing to use the SCS measure despite its limitations. However, the use of the SOCS does limit the ability to compare the scores of self-compassion seen in our sample to that of other research using the SCS. Additionally, it could have interesting to explore the subscales within the SOCS rather than using the total score SOCS. This discussion highlights the difficulty self-compassion research faces in defining and measuring self-compassion, due to the varied definitions and use of total scores within a potentially multidimensional construct. Therefore, it is important for researchers to be clear on the definition of self-compassion they are using, to select a measure that aligns with this definition of this construct and carry out appropriate analysis based on this.

Conclusion

The two papers in this thesis have explored the role of self-compassion in neurological conditions, and for one paper, specifically within FS. Overall, self-compassion been associated with positive outcomes in neurological conditions and appears to be related to other internal processes (such as experiential avoidance or mindfulness). While there is a growing body of research in this area, more is needed in terms of use of randomised control trials, more complex models of interaction with self-compassion and other factors, and the exploration of self-compassion in a wider variety of neurological conditions (including functional neurological conditions). This would enable the development of compassion-cultivating interventions, as well as providing evidence for existing interventions, for neurological conditions.

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Section 4: Ethics

Word count (Research Protocol): 3,868

Megan Hawkes

Lancaster University Doctorate in Clinical Psychology

May 2023

All correspondence should be sent to:

Megan Hawkes
Doctorate in Clinical Psychology
Health Innovation One
Lancaster University
LA1 4AT
Email: m.hawkes@lancaster.ac.uk

Ethics Application

Faculty of Health and Medicine Research Ethics Committee (FHMREC)

Lancaster University

Application for Ethical Approval for Research

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

Title of Project: The Role of Self-compassion and Experiential Avoidance in Functional Seizures

Name of applicant/researcher: Megan Hawkes

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

Grant code (if applicable):

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

Type of study

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

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

SECTION ONE

1. Appointment/position held by applicant and Division within FHM Trainee Clinical Psychologist, Division of Health Research

2. Contact information for applicant:

E-mail: m.hawkes@lancaster.ac.uk **Telephone**: 07719805982 (please give a number on which you can be contacted at short notice)

Address: Doctorate in Clinical Psychology,

Health Innovation One

Sir John Fisher Drive

Lancaster University

Lancaster

LA1 4AT

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

Dr Fiona Eccles, Research Tutor/Supervisor, Lancaster University. DClinPsy and DPhil.

Dr Antonia Kirkby, Consultant Clinical Psychologist, Salford Royal NHS Foundation Trust.

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

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

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

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

4. Project supervisor(s), if different from applicant: 1. Dr Fiona Eccles, 2. Dr Antonia Kirkby

5. **Appointment held by supervisor(s) and institution(s) where based (if applicable)**: 1. Research Tutor, Lancaster University. 2. Clinical Psychologist, Salford Royal NHS Foundation Trust.

SECTION TWO

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

1. Anticipated project dates (month and year)

Start date: End date:

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

Data Management

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

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

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

4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms'

4c. If yes, where relevant has permission / agreement been secured from the website moderator?

4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users?

4e. If no, please give your reasons

5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

6a. Is the secondary data you will be using in the public domain? N/A.

6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.

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

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

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

8. Confidentiality and Anonymity

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

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

9. What are the plans for dissemination of findings from the research?

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

SECTION THREE

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

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

Research has shown self-compassion to play an important role in chronic health conditions in terms of mitigating the amount of negative psychological symptoms one experiences. Self-compassion is a way of relating to one's own suffering with kindness and wanting to actively relieve this.

Whilst there is a wide variety of research into chronic health conditions and self-compassion, there is a lack of research into less 'medically explained' conditions (such as functional conditions) and so this study aims to address this.

This project aims to look at the relationship between self-compassion and outcomes (psychological distress and seizure severity) in those who experience functional seizures. Functional seizures are seizure-like experiences someone can have but without evidence of brain activity seen in a typical epileptic seizure event. In addition, the project will look at whether this relationship is mediated by experiential avoidance. Experiential avoidance is described as attempting to avoid or suppress unwanted internal emotions and experiences and has been identified as being important in functional seizures.

2. **Anticipated project dates (month and year only**)

Start date: December 2021 End date March 2023

Data Collection and Management

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

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

Participants will be adults (18+) with a self-reported diagnosis of functional seizures (also known by other terms such as Non-Epileptic Attack Disorder or Psychogenic Non-Epileptic Seizures). People with epilepsy and functional seizures will be excluded as self-compassion and avoidance in epilepsy has been explored in existing research and epilepsy may confound our results in this population. A demographic questionnaire will aid us in capturing details of other health conditions participants may experience and therefore help us in describing our sample. Participants who experience other functional symptoms will be included. Participants will need to be able to comprehend English to a level in which they would be able to answer the questionnaires due to the measures being standardized for English speaking groups and us not having the means to translate these. The study will not be limited to participants within the UK as recruitment will be worldwide and accessible through social media channels. All genders will be included.

We aim to recruit 100+ participants. We will stop recruiting when we reach 300 participants or at the end of December 2022, whichever is soonest, providing the minimum number has been reached. For the mediation analysis empirical estimates from Fritz and Mackinnon (2007) were used to find the sample size needed for a small or small-medium effect size at both arms of the model. We will use a bias-controlled bootstrap model, using Hayes (2012) Process tool in SPSS and the table in this paper (Fritz & Mackinnon, 2007) suggested that 71 participants would be needed for a medium effect size in both arms and 148 for a small-medium effect in both arms. The maximum participant limit of 300 provides additional power to the model, whilst giving a practical maximum limit in terms of what is needed for the thesis.

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

Participants will be recruited through social media websites such as Facebook, Twitter and Reddit with the support of the charity FND Hope UK who will advertise the study through their social media channels and website also. We will also approach other relevant charities or groups UK and worldwide and ask them to advertise the study on their website and social media channels. We will abide by any research advertising rules given by the charities or groups. The advert shared on these websites will have a link to the study on Qualtrics. All volunteering participants will be included at the point of completing the study if they give their consent on the consent form after reading the participant information sheet. We will make it clear on the consent form that participants need to have a diagnosis of functional seizures.

5. Briefly describe your data collection and analysis methods, and the rationale for their use.

Data will be collected through participants completing questionnaires through Qualtrics (an online survey platform). This will allow for a wide recruitment strategy.

Research Aims:

Predictors: Self-compassion, experiential avoidance, trauma

Outcomes: Quality of life, seizure severity, seizure frequency, depression, anxiety, and stress

Using a quantitative design, the study will aim to address the following questions:

1. Is there a relationship between self-compassion and experiential avoidance in functional seizures? (correlation)
2. Is there a relationship between self-compassion and outcomes in functional seizures? (correlation)
3. Is there a relationship between experiential avoidance and outcomes in functional seizures? (correlation)
4. Is there a difference in experiential avoidance, self-compassion, and outcomes in a those who have experienced trauma and those who have not? (group comparisons)

5. Does experiential avoidance mediate the relationship between self-compassion and outcomes in functional seizures? (mediation)

This study will have a quantitative cross-sectional design. Correlational analysis will be used for each variable to address the research aims as described above. Several mediation analyses will then be conducted, with experiential avoidance being the mediator, self-compassion being the predictor and mood, quality of life, seizure severity and seizures frequency being the outcomes in the models. The design of this study has been created in collaboration with FND Hope (a charity for Functional Neurological Disorders).

Measures:

The measures we will be using are as follows (further psychometric information on the measures can be found in Appendix 1 of the supporting materials document):

- Self-compassion will be measured using The Sussex-Oxford Compassion for the Self Scale (SOCS-S) (Gu et al., 2020). This is a new scale and therefore has not been used in functional seizure research yet but has been used but has been used in research around shame and childhood (Benda & Vyhnánek, 2019), self-compassion in nursing professions (Rizal et al., 2021) and self-compassion in crisis line volunteers (Willems et al., 2021), to give a few examples.

- Avoidance will be measured using the Multidimensional Experiential Avoidance Questionnaire (MEAQ) (Gámez et al., 2011), this measure has been used within functional seizure research (Dimaro et al., 2014).

- Participants will be screened briefly for trauma using the Brief Trauma Questionnaire (BTQ), which is derived from the Brief Trauma Interview [1]. This will aid us in comparing the trauma-experienced group to the no trauma group. A brief measure has been selected as trauma is a secondary question in our study. This measure has been used in PTSD and functional impairment research [2].

The outcomes that will be measured are:

- Seizure severity- Liverpool Seizure Severity Scale (Baker et al., 1998), this measure has been used within functional seizure research (Whitehead et al., 2013).

- Seizure frequency- Self-report

• Mood- DASS – 7 item version (Lovibond & Lovibond, 1995), this measure has been used within functional seizure research (Lawton et al., 2008). We will only be using the depression related items from the 21-item version of the DASS due to the length of our survey and the fatigue our population can experience.

• Seizure-related Quality of Life- Quality of Life in Epilepsy Inventory (QoLIE -31) (Cramer et al., 1998), which has been used in functional seizure research (Avalos et al., 2020).

The measures have been selected with a recent systematic review of outcome measurement in functional neurological disorders taken into consideration (Pick et al., 2020).

6. What plan is in place for the storage, back-up, security, and documentation of data (electronic, digital, paper, etc.)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

Data will be stored on a Lancaster secure cloud (e.g., One Drive) with the researcher and supervisor having access to this data. At the end of the project, the data will then be transferred electronically using a secure method that is supported by the university to the Research coordinator (currently Sarah Heard) who will store the data for 10 years from the end of the project, under the direction of Fiona Eccles who will be the data custodian. This data will be saved on a password protected file space on a university server or One Drive. All data in this project is digital and quantitative. There will be no paper, audio or video data.

7. Will audio or video recording take place? ☒ no ☐ audio ☐ video

a. Please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data.

N/A

b What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

N/A

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

8a. How will you share and preserve the data underpinning your publications for at least 10 years e.g., PURE?

Supporting data will be provided in an electronic format to researchers upon reasonable request. Lancaster University uses Pure as the data repository which will hold, manage, preserve, and provide access to datasets produced by Lancaster University research. This has been discussed with the charity FND Hope.

8b. Are there any restrictions on sharing your data ?

If there is any potential identifiable information in the data (e.g. one person with particular demographic characteristics), this will be removed prior to making the data available or data will be aggregated to prevent identification.

9. Consent

a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law?

Yes.

b. Detail the procedure you will use for obtaining consent?

Participants will be required to read the information sheet and consent form prior to choosing to sign the consent form via selecting the ‘I give consent’ box on Qualtrics. Due to the anonymity of the study, participants will not give their names when giving consent but will be informed of what they are agreeing to and informed that the data they provide will be used for research.

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

Although all reasonable steps have been taken to be sensitive when selecting measures, some participants may find some items emotive. Participants will be advised in the consent form prior to the study that they may stop at any time. Participants will also be presented with another information sheet and consent form prior to the trauma measure at the end of the survey. This sheet will provide information about the nature of the questions they will be asked, prompt self-care and give participants the option to end the study at this point or provide consent to continue to the trauma measure. Due to the data being anonymous, when a participant has completed the study, it will not be possible to identify their dataset as theirs and therefore delete it if they request. Participants will be made aware of this through the consent form. We will provide suggested sources of support in both the information sheet and the debrief sheet for participants.

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

None. Due to the study taking place online, there will be no lone working. Should any unexpected risk or distressing feeling arise these will be discussed with my supervisors. Any contact details given during the process of the study will be work contact details only (such as a Lancaster email), not personal.

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

There may be no direct benefit to participants in completing the study and participants will be made aware of this in the information sheet. However, participants may find taking part in the study interesting. This study could potentially encourage more research in the area of functional seizures.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

None.

14. Confidentiality and Anonymity

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

b. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.

The data collected will be anonymous and if there is any identifiable data (such as only one participant within an ethnicity group or diagnosis) then this data will be aggregated before sharing with any researchers who have requested the data. The approach to aggregating this data will be dependant on the issue of identifiability at the time. For example, if one person in the sample has an age very different from that of the rest of the sample, if the data is shared with other researchers ages can be placed into categories. The suggestion given by FHMREC of aggregating taking place at 5 participants or less will be followed as a guide.

The questionnaires used do not include options for 'free text' and the research is quantitative so direct quotes will not be used. Participants will be in control of where and when they choose to complete the study and so confidentiality in this sense will be in control of the participant. None of the measures used have the option of disclosing harm to self or others as due to the anonymous and international nature of the study we would not be able to aid/intervene in this.

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

Throughout the research design, measure selection and survey creation process the charity FND Hope UK (which provides support to people with functional neurological conditions including functional seizures) have been involved and continue to be involved. A representative from this charity is an expert by experience in the area of Functional Neurological Disorders. This representative has provided consultation and feedback on all aspects of the recruitment process, including reviewing a draft of the survey. We have been grateful for this consultation and feedback and have made alterations to the study as needed.

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

The research will be written into a thesis as part of the fulfilment of the Doctorate of Clinical Psychology qualification. It is hoped that the results of the research will later be submitted for publication in an academic/professional journal. Outcomes will be shared with FND Hope who will disseminate to their audiences.

The study will be presented at appropriate conferences. The study will also be presented during Lancaster University's Thesis presentation day.

17. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC?

The study includes a short trauma measure. This may be triggering or emotive and due to the anonymous nature of the study we would not be able to provide support. To address this, we will include contact details for other sources of support, as previously described. However, due to the international nature of the study, some people may not be able to access some of these methods of support and would have to find the relevant support details for their country/location/accessibility issues.

SECTION FOUR: signature

Applicant electronic signature: Megan Hawkes Date 04/11/2021

Student applicants: please tick to confirm that your supervisor has reviewed your application, and that they are happy for the application to proceed to ethical review ☒

Project Supervisor name (if applicable): Fiona Eccles Date application discussed 29/10/2021

Submission Guidance

1. Submit your FHMREC application by email to Becky Case (fhmresearchsupport@lancaster.ac.uk) as two separate documents:
    i. **FHMREC application form.**
    Before submitting, ensure all guidance comments are hidden by going into 'Review' in the menu above then choosing *show markup>balloons>show all revisions in line.*
    ii. **Supporting materials.**
    Collate the following materials for your study, if relevant, into a single word document:
        a. Your full research proposal (background, literature review, methodology/methods, ethical considerations).
        b. Advertising materials (posters, e-mails)
        c. Letters/emails of invitation to participate
        d. Participant information sheets
        e. Consent forms
        f. Questionnaires, surveys, demographic sheets
        g. Interview schedules, interview question guides, focus group scripts
        h. Debriefing sheets, resource lists

Please note that you DO NOT need to submit pre-existing measures or handbooks which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.

2. Submission deadlines:
    i. Projects including direct involvement of human subjects **[section 3 of the form was completed]**. The *electronic* version of your application should be submitted to Becky Case **by the committee deadline date.** Committee meeting dates and application submission dates are listed on the FHMREC website. Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application. Please ensure you are available to attend the committee meeting (either in person or via telephone) on the day that your application is considered, if required to do so.

ii. The following projects will normally be dealt with via chair’s action, and may be submitted at any time. **[Section 3 of the form has *not* been completed, and is not required].** Those involving:

  a. existing documents/data only;
  b. the evaluation of an existing project with no direct contact with human participants;
  c. service evaluations.

3. <u>You must submit this application from your Lancaster University email address, and copy your supervisor in to the email in which you submit this application</u>

Research Protocol

Title

The Role of Self-compassion and Experiential Avoidance in Functional Seizures.

Research Team

Megan Hawkes, Trainee Clinical Psychologist, Lancaster Doctorate of Clinical Psychology

Dr Fiona Eccles, Lecturer, Lancaster University

Dr Antonia Kirkby, Consultant Clinical Neuropsychologist, Salford Royal NHS Foundation Trust

Study Rationale

Functional seizure disorder is also known as non-epileptic attack disorder (NEAD), psychogenic nonepileptic seizures (PNES) and occasionally ‘dissociative seizures’ or ‘conversion disorder’. There is no current universal terminology, but it has been proposed that ‘functional seizures’ is a more neutral term for both patients and clinicians and could potentially encourage multi-disciplinary management of this disorder [3] and therefore this term will be used for the current research. Functional seizures are paroxysmal events similar to those in epilepsy, but these events are not a result of abnormal brain functioning seen in electroencephalograms, as seen in epilepsy (Asadi-Pooya et al., 2020). Whilst the underlying mechanisms and models of functional seizures are debated, a proportion (although not all) of those experiencing functional seizures report also experiencing a history of trauma [4]. Childhood trauma is more often reported in those with functional seizures when compared to those with epilepsy [5] and a history of trauma is more prevalent in those with functional seizures than in those who have other functional neurological symptoms [6]. The type of trauma experienced could be an important factor. In a study, those with functional seizures reported higher rates of sexual or ‘other’ trauma compared to the epilepsy group [7]. It could therefore be important to capture information on the type of trauma, if any, a person with functional seizures has experienced.

One potentially important psychological construct for people who experience functional seizures is avoidance. Experiential avoidance has been commonly found in those with functional seizures [8] and research has suggested this group have more avoidant coping styles than controls [9]. The anxiety and avoidance a person with functional seizures experiences could also impact the frequency of their seizures [10]. Experiential avoidance can be described as a reluctance to experience difficult feelings, thoughts and sensations and attempts to control or escape these experiences [11]. It is suggested that by attempting to inhibit these uncomfortable feelings, thoughts, and sensations, one can inadvertently increase the frequency and distress of these experiences [12,13]. While engaging in experiential avoidance is linked to higher levels of psychological distress [14,15] in clinical and non-clinical populations, it is also possible that by engaging in this a person reduces their ability to experience more positive emotions or events [16]. Therefore, generally by engaging in experiential avoidance a person can increase their experience of psychological distress and impede their positive life experiences.

A systematic review of experiential avoidance literature suggested that experiential avoidance mediates the relationship between trauma and psychological distress. The review also noted that experiential avoidance predicts the severity of symptoms in some psychological disorders and mediates the relationship between maladaptive coping, self-regulatory strategies and psychological distress [17]. Despite these links being drawn between experiential avoidance, trauma, and psychological distress in clinical and non-clinical populations, there is minimal research into these potential relationships in functional seizures. As people with functional seizures are more likely to engage in experiential avoidance [18] and more likely to report experiencing trauma than people with epilepsy [19], it could be important to explore whether engaging in experiential avoidance influences the psychological distress and physiological outcomes a person with functional seizures experiences.

Whilst a multitude of variables can influence a person's wellbeing, one that has emerged in recent literature is self-compassion. Compassion can be described as a sensitivity to suffering in ourself and others, with a commitment to try to alleviate and prevent it [20–22]. Gilbert [20] suggests that compassion is a 'social mentality' that can flow in three directions; compassion we feel from others, compassion we direct to others and compassion we feel towards ourselves (self-compassion). In research, low levels of self-compassion are related to psychological difficulties across various populations, as seen in a systematic review [23], suggesting that self-compassion is an important construct in mental health. Further examples of this are seen in research with non-clinical populations where higher self-compassion has been associated with greater resilience [24], less stress [25], less anxiety [26] and less depression [27].

Whilst higher levels self-compassion appear to be beneficial generally in terms of 'buffering' against negative affect or psychopathology, research has explored its importance in people experiencing health conditions specifically. A systematic review into chronic health conditions and self-compassion-related interventions found that many of the therapies explored were associated with an improvement in outcomes such as anxiety, depression, and stress [28]. This not only suggests a relationship between self-compassion and psychological outcomes in populations with chronic health conditions, but also suggests that self-compassion can be practised, as reported by Gilbert [20].

Whilst self-compassion has been explored in a variety of health conditions there is less research into this within less medically understood or idiopathic conditions such as functional neurological disorders, fibromyalgia, and chronic fatigue syndrome despite suggestions that these groups may experience challenges such as greater stigma than conditions with clearer medical understanding (Looper & Kirmayer, 2004).

There is limited research into the role of self-compassion in those who experience functional seizures. The research that has been conducted suggests that self-compassion is related to better adjustment (measured by coping efficacy, quality of life, anxiety and depression) in those with functional seizures [29]. Given that self-compassion could be argued to be an important construct in mental health and, in those with health conditions, further research is needed into the role of self-compassion in functional seizures.

Additionally, a link between self-compassion and experiential avoidance has been explored in research. Experiential avoidance could be argued to be a form of coping (choosing to cope by not engaging in unwanted thoughts, feelings, and sensations) and research has suggested that the coping strategies people with health conditions use can be influenced by self-compassion [30–32]. Indeed, avoidance has been shown to negatively correlate with self-compassion, with people who have high compassion engaging in fewer avoidance strategies [33]. Furthermore, a mediation analysis found that avoidance and activation were significant mediators of the relationship between self-compassion and depressive symptoms, in a non-clinical population [34]. This suggests that self-compassion could affect the level of avoidance a person adopts and this in turn could impact on psychological outcomes. Considering these links, it could be important to look at the roles of self-compassion and experiential avoidance in this (sometimes trauma experienced) population and how this impacts psychological outcomes for this population.

With existing research exploring relationships between self-compassion and outcomes, and self-compassion and avoidance, we propose a mediation study. This study will look at whether experiential avoidance mediates the relationship between self-compassion and psychological outcomes for those who experience functional seizures. The outcomes measured will be quality of life, depression, seizure severity and seizure frequency. As a secondary research question, we will also look at whether there is a difference in level of self-compassion, level of experiential avoidance, and outcomes in a trauma experienced and non-trauma experienced group.

Firstly, we will try to replicate previous studies in demonstrating relationships between experiential avoidance, self-compassion, and outcomes (with higher self-compassion being associated with lower avoidance, lower distress, and higher quality of life). We will also demonstrate relationships between experiential avoidance and the stated outcomes. After this we will conduct mediation analyses to see whether experiential avoidance mediates the relationship between self-compassion and the stated outcomes. The proposed research study would be beneficial in terms of contributing to an understanding of processes within functional seizures which could contribute to the future development of effective interventions.

Design and Research Questions

This study will investigate the relationships between trauma, self-compassion, experiential avoidance and several psychological and physiological outcomes.

Predictors: Self-compassion, experiential avoidance, trauma

Outcomes: Quality of life, seizure severity, seizure frequency and depression.

Using a quantitative design, the study will aim to address the following questions:

1. Is there a relationship between self-compassion and experiential avoidance in functional seizures? (correlation)
2. Is there a relationship between self-compassion and the outcomes in functional seizures? (correlation)

3. Is there a relationship between experiential avoidance and the outcomes in functional seizures? (correlation)
4. Is there a difference in experiential avoidance, self-compassion, and outcomes in those with functional seizures who have experienced trauma and those who have not? (Group comparisons)
5. Does experiential avoidance mediate the relationship between self-compassion and outcomes in functional seizures? (mediation)

This study will have a quantitative cross-sectional design. Correlational analysis will be used for each variable to address the research aims as described above. Several mediation analyses will then be conducted, with experiential avoidance being the mediator, self-compassion being the predictor and mood, quality of life, seizure severity and seizures frequency being the outcomes in the models. The design of this study has been created in collaboration with FND Hope (a charity for Functional Neurological Disorders).

Method

Participants

Participants will be adults (aged 18+) with a self-reported diagnosis of functional seizures (or any similar diagnosis such as NEAD, PNES etc). People with epilepsy and functional seizures will be excluded. Participants who experience other functional symptoms as well as seizures (e.g., fatigue, functional movement symptoms etc) will be included as individuals often experience more than one symptom. A demographic questionnaire will aid us in capturing details of other health conditions participants may experience and therefore help in describing our sample. Participants will need to be able to comprehend English to a level in which they would be able to answer the questionnaires. The study will not be limited to participants within the UK as recruitment will be worldwide and accessible through social media channels. We aim to recruit 100+ participants. We will stop recruiting when we reach

300 participants or in December 2022, whichever is soonest, providing the minimum number has been reached.

For the mediation analysis empirical estimates from Fritz and Mackinnon [35] were used to find the sample size needed for a small or small-medium effect size at both arms of the model. We will use a bias-controlled bootstrap model, using Hayes [36] Process tool in SPSS and the table in this paper [35] suggested that 71 participants would be needed for a medium effect size in both arms and 148 for a small-medium effect in both arms.

Proposed analysis

Correlational analyses will be used to see if there is a relationship between variables. This will be used to see if there is a relationship between: self-compassion and experiential avoidance, self-compassion and outcomes, experiential avoidance and outcomes, trauma level and self-compassion, and trauma level and experiential avoidance. The Hayes Process tool (2012) will be used to investigate whether avoidances mediates the relationship between self-compassion and outcomes. There will be separate mediation analyses for each outcome.

Measures

The measures we will be using are as follows (further psychometric information on the measures can be found in Appendix 1.):

Predictors

- Self-compassion will be measured using The Sussex-Oxford Compassion for the Self Scale (SOCS-S) [37]. This is a new scale and therefore has not been used in functional seizure research yet but has been used in research around shame and childhood [38], self-compassion in nursing professions [39] and self-compassion in crisis line volunteers [40], to give a few examples.

- Avoidance will be measured using the Multidimensional Experiential Avoidance Questionnaire (MEAQ) [41], this measure has been used within functional seizure research [10].
- Participants will be screened briefly for trauma using the Brief Trauma Questionnaire (BTQ), which is derived from the Brief Trauma Interview (Schnurr et al., 2002). This will aid us in comparing the trauma-experienced group to the no trauma group. A brief measure has been selected as trauma is a secondary question in our study. This measure has been used in PTSD and functional impairment research (Donahue et al., 2017).

The outcomes that will be measured are:

- Seizure severity- Liverpool Seizure Severity Scale [42] this measure has been used within functional seizure research [43].
- Seizure frequency- Self-report within the demographic questionnaire.
- Mood- DASS – 7 item version (Lovibond & Lovibond, 1995), this measure has been used within functional seizure research (Lawton et al., 2008). We will only be using the depression related items from the 21-item version of the DASS due to the length of our survey and the fatigue our population can experience.
- Seizure-related Quality of Life- Quality of Life in Epilepsy Inventory (QoLIE-31) [44], which has been used in functional seizure research [45].

The measures have been selected with a recent systematic review of outcome measurement in functional neurological disorders taken into consideration [46].

Procedure

Participants will be invited to take part in the research through coming across adverts on social media channels and the study will be widely distributed. Examples of platforms include the researcher’s twitter account (set up for the purposes of the study), Reddit and the charity FND Hope’s social media channels. Participants will be able to follow a link which will take them to the Qualtrics webpage. They will then be able to view the Participant Information Sheet which will include information such as a study description, its purpose and information on how the data may be used. If the participant chooses to take part in the study the webpage will direct them to the consent form and if consent is obtained, then they will be presented with the measures to complete. Data will be collected as the participant continues through the study and so if a participant does not complete later measures, data from earlier measures may still be viewed and potentially included in analysis. Participants will be made aware of the fact their data cannot be withdrawn at a later stage as it will be anonymous and therefore, we will not be able to identify their data as theirs. This will be made clear on the information sheet. Participants will be able to download a version of the consent form, information sheet and debrief sheet. Participants will be presented with another information sheet prior to the trauma measure at the end of the survey. This sheet will provide information about the nature of the questions they will be asked, prompt self-care and give participants the option to end the study at this point or provide consent to continue on to the trauma measure.

Data Storage

During the project, data will be stored on a Lancaster secure cloud (e.g. One Drive) with the researcher and supervisor having access to this data. At the end of the project, the data will then be transferred electronically using a secure method that is supported by the university to the Research coordinator (currently Sarah Heard) who will store the data for 10 years from the end of the project, under the direction of Fiona Eccles who will be the data custodian. This data will be saved on a password protected file space on a university server or One

Drive. All data in this project is digital and quantitative. There will be no paper, audio or video data.

Dissemination

It is hoped that the findings will be written up and submitted to a peer-reviewed journal. The research will be written into a thesis as part of the fulfilment of the Doctorate of Clinical Psychology qualification. Outcomes will be shared with FND Hope who will disseminate to their audiences. The study may be presented at appropriate conferences and special interest groups. The study will also be presented during Lancaster University's Thesis presentation day.

Practical issues (e.g., costs/logistics)

The mediation analysis will need a somewhat large sample size, and this will be addressed by adopting a broad recruitment strategy. All measures used are free to use for research at the time of writing.

Potential Limitations

The study will rely on participants self-reporting that they have had a diagnosis of functional seizures and therefore we will not be able to evidence definitively that all our sample have received that diagnosis.

Ethical concerns

There are no anticipated significant risks to participants or substantial ethical concerns. Although all reasonable steps have been taken to be sensitive when selecting measures, some participants may find some items emotive. Participants will be advised in the consent form prior to the study that they may stop at any time. There will also be an additional page presented prior to the trauma questionnaire advising participants of the nature of the following questions and encouraging self-care. Participants can choose to end the study at this point and skip the trauma questionnaire or can choose to continue and complete the trauma questionnaire. Due to the data being anonymous, when a participant has completed the study, it will not be possible to identify their dataset as theirs and therefore delete it if they request. Participants will be made aware of this through the consent form. We will provide suggested sources of support in both the information sheet and the debrief sheet for participants.

Public involvement

The charity FND Hope have been involved within the creation of the study and will be involved in the recruitment stage also. The advocate from this charity who we are in contact with is Dawn Golder. FND Hope will be involved in the recruitment of participants as well as having been involved in the selection of materials in the study to ensure they are accessible and meaningful for this population.

Timescale

Time	Project
November 2021	Submit documents for ethical approval to FHMREC
December 2021/January 2022	If ethical approval has been granted, then data collection begins. Advertise survey through social media and FND Hope’s social media channels
August-December 2022	Data collection ends. Data inputted into relevant software and data analysis
Jan - February 2023	Submit draft of results and discussion
March 2023	Submit thesis to Lancaster University
September 2023	Submit manuscript for publication

Appendices

Appendix 1

Measures chosen for survey

Scale	Reference	Number of Items	Internal Reliability (Cronbach's alpha)	Previous use in Functional Seizure Research
Liverpool Seizure Severity Scale 2.0 (LSSS)	Scott-Lennox, J., Bryant-Comstock, L., Lennox, R., & Baker, G. A. (2001). Reliability, validity and responsiveness of a revised scoring system for the Liverpool Seizure Severity Scale. *Epilepsy Research*, *44*(1), 53–63. https://doi.org/10.1016/s0920-1211(01)00186-3	12	*a*=0.66-0.87	E.g. Rawlings, G. H., Brown, I., & Reuber, M. (2017). Predictors of health-related quality of life in patients with epilepsy and psychogenic nonepileptic seizures. Epilepsy & behavior : E&B, 68, 153–158. https://doi.org/10.1016/j.yebeh.2016.10.035
Sussex-Oxford Compassion for the Self Scale (SOCS-S)	Gu, J., Baer, R., Cavanagh, K., Kuyken, W., & Strauss, C. (2020). Development and psychometric properties of the Sussex-Oxford compassion scales (SOCS). *Assessment*, *27*(1), 3-20.	20	*a*=0.75-0.93	At the time of writing the SOCS-S has not yet been used in functional seizure research.
Multidimensional Experiential Avoidance Questionnaire (MEAQ)	Gámez, W., Chmielewski, M., Kotov, R., Ruggero, C., & Watson, D. (2011). Development of a measure of experiential avoidance: The Multidimensional Experiential	62	*a*=0.91-0.92	E.g. Dimaro, L. V., Dawson, D. L., Roberts, N. A., Brown, I., Moghaddam, N. G., & Reuber, M. (2014). Anxiety and avoidance in psychogenic nonepileptic seizures: the role of implicit and explicit anxiety. *Epilepsy & Behavior*, *33*, 77-86.

	Avoidance Questionnaire. *Psychological assessment*, *23*(3), 692.			
The Depression, Anxiety and Stress Scale-21 (DASS-21) (only the 7 depression items will be used)	Lovibond, P. F., & Lovibond, S. H. (1995). The structure of negative emotional states: Comparison of the Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories. *Behaviour research and therapy*, *33*(3), 335-343.	7	Depression *a*=0.91, Anxiety *a*=0.81, Stress *a*=0.89	E.g. Hamed, S. A., Attiah, F. A., & Fawzy, M. (2020). Psychogenic nonepileptic seizures in adults with epilepsy: a tertiary hospital-based study. *International Journal of Neuroscience*, *130*(5), 522-532.
Quality of Life in Epilepsy Inventory-31 (QOLIE-31)	Cramer, J.A., Perrine, K., Devinsky, O., Bryant-Comstock, L., Meador, K. and Hermann, B. (1998), Development and Cross-Cultural Translations of a 31-Item Quality of Life in Epilepsy Inventory. *Epilepsia*, *39*: 81-88	31	*a*= 0.77-0.93	E.g Avalos, J. C., Silva, B. A., Echazu, M. F. T., Rosso, B., Besocke, A. G., & del Carmen Garcia, M. (2020). Quality of life in patients with epilepsy or psychogenic nonepileptic seizures and the contribution of psychiatric comorbidities. *Epilepsy & Behavior, 112,* 107447.
The Brief Trauma Questionnaire (BTQ)	Schnurr, P.P., Spiro, A. III, Vielhauer, M.J., Findler, M.N., & Hamblen, J.L. (2002). Trauma in the lives of older men: Findings from the Normative Aging Study.	10	N/A	Donahue, J. J., Huggins, J., & Marrow, T. (2017). Posttraumatic stress symptom severity and functional impairment in a trauma-exposed sample: A preliminary examination into the moderating role of valued living. Journal of *Contextual Behavioral Science, 6(*1), 13-20.

	Journal of Clinical Geropsychology, 8, 175-187.			
Demographic and Illness-related information	N/A	10	N/A	N/A

Total number of items: 152

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Appendix 4-1 Approval email

From: FHM Research Ethics <fhmresearchsupport@lancaster.ac.uk>
Date: Tuesday, 21 December 2021 at 13:44
To: Hawkes, Meg (Postgrad Researcher) <m.hawkes@lancaster.ac.uk>
Cc: Eccles, Fiona <f.eccles@lancaster.ac.uk>, Keegan, Thomas <t.keegan@lancaster.ac.uk>
Subject: Ethics approval FHMREC21036 The Role of Self-Compassion and Experiential Avoidance in Functional Seizures
Dear Meg,

Thank you for submitting your application and additional information for *The Role of Self-Compassion and Experiential Avoidance in Functional Seizures.* The information you provided has been reviewed by members of the Faculty of Health and Medicine Research Ethics Committee and I can confirm that approval has been granted for this project.

As principal investigator your responsibilities include:

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

Please do not hesitate to contact me if you require further information about this.

Best wishes,

Debbie

Debbie Knight | Research Ethics Officer pp FHM REC
Secretary FASS & LUMS Research Ethics Committee & UREC | Research and Enterprise Services
Lancaster University |
Contact me on Teams
https://www.lancaster.ac.uk/Research Ethics

Appendix 4-2 Survey

Participant Information Sheet

The Role of Self-compassion and Experiential Avoidance in Functional Seizures

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

My name is Megan Hawkes, and I am conducting this research as a student in the Doctorate of Clinical Psychology programme at Lancaster University, Lancaster, United Kingdom. A downloadable copy of the information sheet can be accessed here: Link

What is the study about?

The purpose of this study is to explore psychological factors which could affect outcomes in people who experience functional seizures. In particular we are looking at self-compassion (whether people are kind to themselves) and experiential avoidance (e.g., trying to avoid difficult feelings) to see whether they are important for wellbeing in people with functional seizures. We hope that this will contribute to the research base and understanding of functional seizures and that this will influence the psychological support available for those who experience functional seizures.

Why have I been approached?

You have been approached because the study requires information from people who are aged 18 years and over and who have diagnosed functional seizures (or Non-Epileptic Attack Disorder or Psychogenic Non-epileptic Seizures or any similar diagnosis), but who do not also have a diagnosis of epilepsy.

Do I have to take part?

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

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

If you decide you would like to take part, you would be asked to complete an online questionnaire, which will ask you questions about; how you feel towards yourself, how you manage difficult feelings, how often you experience functional seizures, the impact of functional seizures on your daily life, your current mental health and demographic information. At the end of the questionnaires, there is an option to complete an additional questionnaire about trauma if this is something you have experienced.

It will take approximately 25 minutes to complete the online questionnaire and an additional 10 minutes if you choose to complete the trauma questionnaire at the end.

Will my data be Identifiable?

The information you provide will be anonymous, so no one will know that the data is yours. The data collected for this study will be stored securely using university approved secure cloud storage.

- At the end of the study, data will be kept securely in on the university's secure server for ten years. At the end of this period, they will be destroyed.
- The dataset may be published; but data will be anonymous, and any identifiable elements will be excluded.
- **Please note:** Due to the data being anonymous, we will be unable to delete your data if requested as we will not be able to identify the data as yours.

What will happen to the results?

The results will be summarised and reported as part of a thesis within the Lancaster University Doctorate in Clinical Psychology programme. Following this, the report may be submitted for publication in an academic or professional journal. The outcomes of this study will be shared with the charity FND Hope who will disseminate to their audiences. The study may be presented at appropriate conferences and will also be presented during Lancaster University's Thesis presentation day.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to contact the resources provided at the end of this sheet. If you experience any distress after participating in the study, please also contact these organisations.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?

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

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the lead researcher by post or email:

Megan Hawkes
Trainee Clinical Psychologist
Faculty of Health and Medicine
Lancaster University
Health Innovation One
Sir John Fisher Drive
Lancaster University
Lancaster

Dr Fiona Eccles
Research supervisor
Faculty of Health and Medicine
Lancaster University
Health Innovation One
Sir John Fisher Drive
Lancaster University
Lancaster

LA1 4AT
Email: m.hawkes@lancaster.ac.uk

LA1 4AT
Email: f.eccles@lancaster.ac.uk
Telephone: (+44) 01524 592807

Complaints
If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact Dr Ian Smith.

Dr Ian Smith
Research Director
Doctorate in Clinical Psychology
Health Innovation One
Sir John Fisher Drive
Lancaster University
Lancaster
LA1 4AT
Phone: +44 1524 592282
Email: i.smith@lancaster.ac.uk

If you wish to speak to someone outside of the Lancaster Doctorate Programme, you may also contact:

Dr Laura Machin Tel: +44 (0)1524 594973
Chair of FHM REC Email: l.machin@lancaster.ac.uk
Faculty of Health and Medicine
(Lancaster Medical School)
Lancaster University
Lancaster
LA1 4YG

Thank you for taking the time to read this information sheet.

Resources in the event of distress

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

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

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

FND Hope International
https://fndhope.org/contact/

Health & Medicine | Lancaster University

Eligibility

To be eligible to participate in this study you must be 18 years of age or older and experience functional seizures but not have a diagnosis of epilepsy. To be able to continue please check each statement to confirm you are eligible to participate in this study.

☐ I am 18 years of age or older

☐ I have been diagnosed with functional seizures/ Non-Epileptic Attack Disorder (NEAD)/ Psychogenic Non-Epileptic Seizures (PNES), Psychogenic Seizures

☐ I do not have a diagnosis of epilepsy.

Health & Medicine | Lancaster University

Consent Form

Study Title: The Role of Self-compassion and Experiential Avoidance in Functional Seizures

We are asking if you would like to take part in a research project that explores psychological factors in functional seizures and their effect on outcomes in functional seizures. Before you consent to participating in the study, we ask that you read the participant information sheet and click on the statement if you agree. If you have any questions or queries before completing the consent form please speak to the principal investigator, Megan Hawkes at m.hawkes@lancaster.ac.uk.

A downloadable version of the consent form can be accessed here: Link

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

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

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

☐ I consent

☐ I do not consent

Demographic Questionnaire

Age (please type your age)	________
Gender (please select)	Male Female Non-binary Other Prefer not to say
Ethnicity (please type)	_______
Country of residence (please type)	________
Additional diagnosis (apart from NEAD/FS) (please select)	Functional Neurological Disorder Depression Anxiety Other: ________ None
Employment status (please select)	Employed Full-time Employed Part-time Student/Apprenticeship Full-time unpaid carer Signed off of work- sickness Retired Unable to work- receiving disability benefits Unable to work- not receiving disability benefits Maternity/Paternity leave Other: _______

Age at time of diagnosis (please type)	__________
NEAD/FS diagnosis method (select all that apply) (please select)	MRI EEG and video By General Practitioner/Family Doctor In hospital Other: ________
Frequency of NEA’s/Functional Seizures (please select)	I am currently not experiencing functional seizures I have functional seizures once or a few times a year but not every month I typically have functional seizures 1-3 times a month I typically have functional seizures 4 or more times a month but not weekly I typically have functional seizures 1-3 times a week I have functional seizures 4 or more times per week but not daily I have functional seizures daily or almost every day

Measures

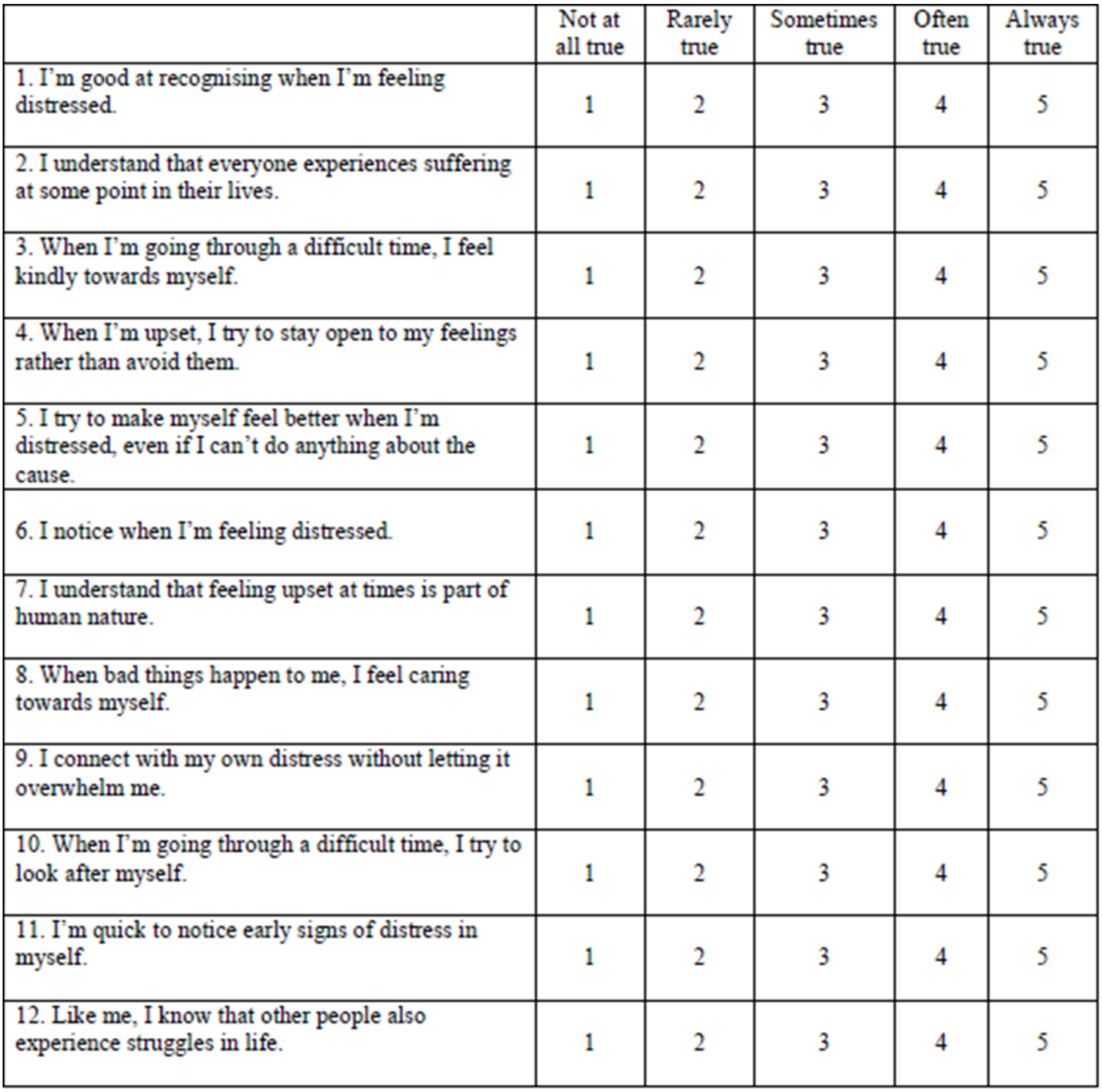
Self-compassion

Sussex-Oxford Compassion for the Self Scale (SOCS-S)

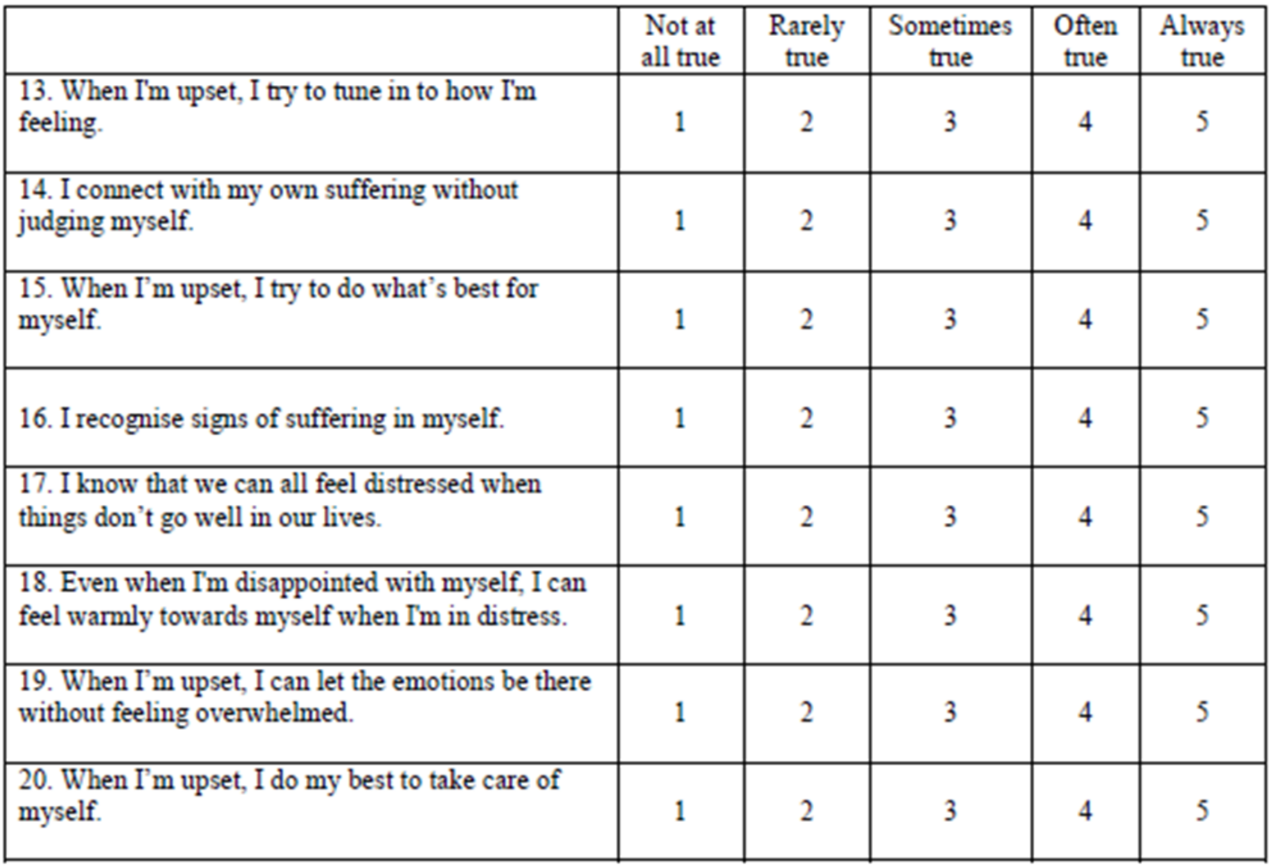
Instructions

Below are statements describing how you might relate to **yourself**. Please indicate how true the following statements are of you using the 5-point response scale (1 = Not at all true, 2 = Rarely true, 3 = Sometimes true, 4 = Often true, 5 = Always true). For example, if you think that a statement is often true of you, circle '4'.

Note: In the below items, generic terms (e.g., 'upset', 'distress', 'suffering', struggling') are used to cover a range of unpleasant emotions, such as sadness, fear, anger, frustration, guilt, shame, etc. Please provide an answer for each statement.

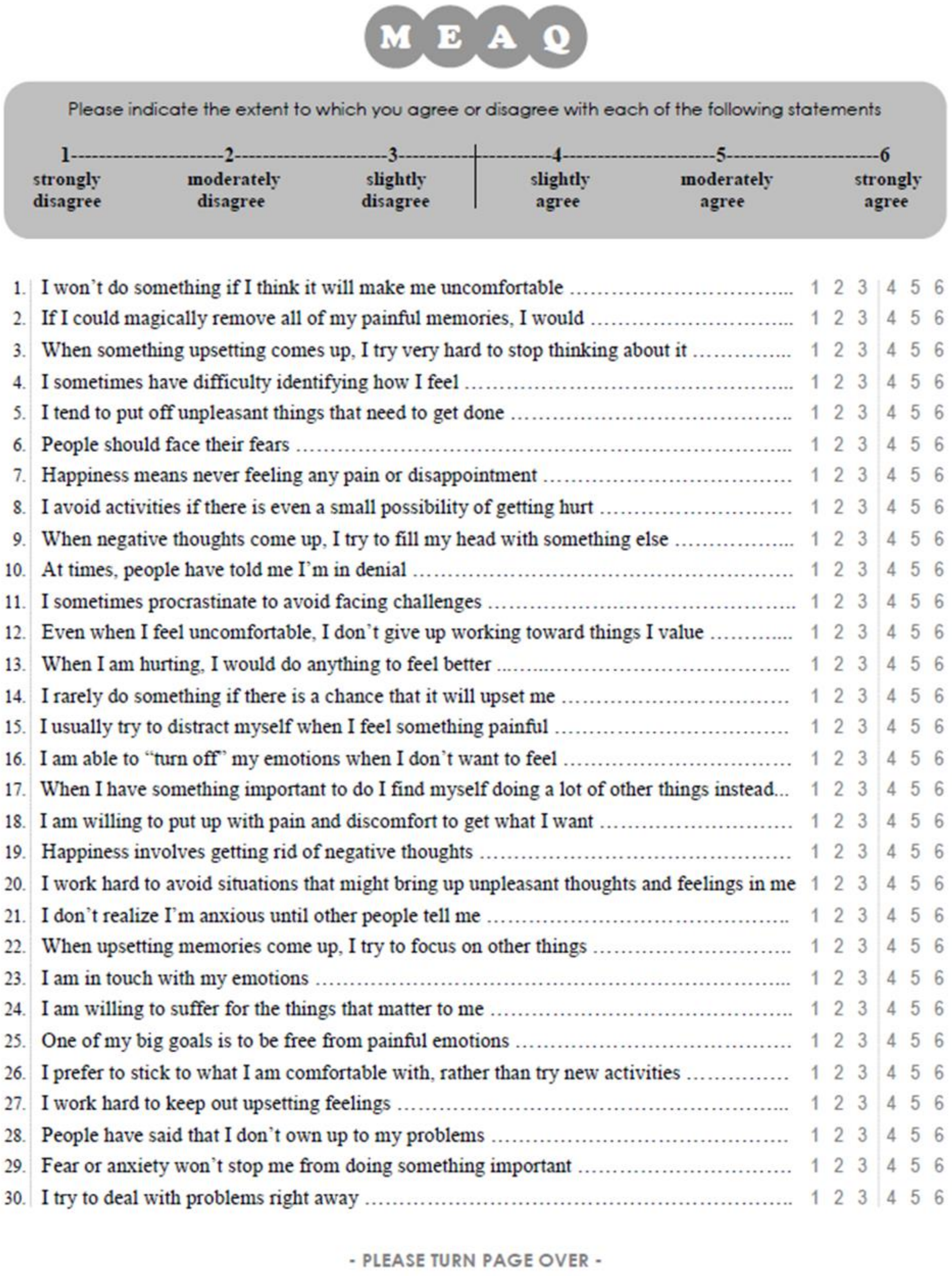


	Not at all true	Rarely true	Sometimes true	Often true	Always true
1. I'm good at recognising when I'm feeling distressed.	1	2	3	4	5
2. I understand that everyone experiences suffering at some point in their lives.	1	2	3	4	5
3. When I'm going through a difficult time, I feel kindly towards myself.	1	2	3	4	5
4. When I'm upset, I try to stay open to my feelings rather than avoid them.	1	2	3	4	5
5. I try to make myself feel better when I'm distressed, even if I can't do anything about the cause.	1	2	3	4	5
6. I notice when I'm feeling distressed.	1	2	3	4	5
7. I understand that feeling upset at times is part of human nature.	1	2	3	4	5
8. When bad things happen to me, I feel caring towards myself.	1	2	3	4	5
9. I connect with my own distress without letting it overwhelm me.	1	2	3	4	5
10. When I'm going through a difficult time, I try to look after myself.	1	2	3	4	5
11. I'm quick to notice early signs of distress in myself.	1	2	3	4	5
12. Like me, I know that other people also experience struggles in life.	1	2	3	4	5



	Not at all true	Rarely true	Sometimes true	Often true	Always true
13. When I'm upset, I try to tune in to how I'm feeling.	1	2	3	4	5
14. I connect with my own suffering without judging myself.	1	2	3	4	5
15. When I'm upset, I try to do what's best for myself.	1	2	3	4	5
16. I recognise signs of suffering in myself.	1	2	3	4	5
17. I know that we can all feel distressed when things don't go well in our lives.	1	2	3	4	5
18. Even when I'm disappointed with myself, I can feel warmly towards myself when I'm in distress.	1	2	3	4	5
19. When I'm upset, I can let the emotions be there without feeling overwhelmed.	1	2	3	4	5
20. When I'm upset, I do my best to take care of myself.	1	2	3	4	5

Experiential Avoidance



MEAQ

Please indicate the extent to which you agree or disagree with each of the following statements

1	2	3	4	5	6
strongly disagree	moderately disagree	slightly disagree	slightly agree	moderately agree	strongly agree

1. I won't do something if I think it will make me uncomfortable .... 1 2 3 | 4 5 6
2. If I could magically remove all of my painful memories, I would .... 1 2 3 | 4 5 6
3. When something upsetting comes up, I try very hard to stop thinking about it .... 1 2 3 | 4 5 6
4. I sometimes have difficulty identifying how I feel .... 1 2 3 | 4 5 6
5. I tend to put off unpleasant things that need to get done .... 1 2 3 | 4 5 6
6. People should face their fears .... 1 2 3 | 4 5 6
7. Happiness means never feeling any pain or disappointment .... 1 2 3 | 4 5 6
8. I avoid activities if there is even a small possibility of getting hurt .... 1 2 3 | 4 5 6
9. When negative thoughts come up, I try to fill my head with something else .... 1 2 3 | 4 5 6
10. At times, people have told me I'm in denial .... 1 2 3 | 4 5 6
11. I sometimes procrastinate to avoid facing challenges .... 1 2 3 | 4 5 6
12. Even when I feel uncomfortable, I don't give up working toward things I value .... 1 2 3 | 4 5 6
13. When I am hurting, I would do anything to feel better .... 1 2 3 | 4 5 6
14. I rarely do something if there is a chance that it will upset me .... 1 2 3 | 4 5 6
15. I usually try to distract myself when I feel something painful .... 1 2 3 | 4 5 6
16. I am able to "turn off" my emotions when I don't want to feel .... 1 2 3 | 4 5 6
17. When I have something important to do I find myself doing a lot of other things instead... 1 2 3 | 4 5 6
18. I am willing to put up with pain and discomfort to get what I want .... 1 2 3 | 4 5 6
19. Happiness involves getting rid of negative thoughts .... 1 2 3 | 4 5 6
20. I work hard to avoid situations that might bring up unpleasant thoughts and feelings in me 1 2 3 | 4 5 6
21. I don't realize I'm anxious until other people tell me .... 1 2 3 | 4 5 6
22. When upsetting memories come up, I try to focus on other things .... 1 2 3 | 4 5 6
23. I am in touch with my emotions .... 1 2 3 | 4 5 6
24. I am willing to suffer for the things that matter to me .... 1 2 3 | 4 5 6
25. One of my big goals is to be free from painful emotions .... 1 2 3 | 4 5 6
26. I prefer to stick to what I am comfortable with, rather than try new activities .... 1 2 3 | 4 5 6
27. I work hard to keep out upsetting feelings .... 1 2 3 | 4 5 6
28. People have said that I don't own up to my problems .... 1 2 3 | 4 5 6
29. Fear or anxiety won't stop me from doing something important .... 1 2 3 | 4 5 6
30. I try to deal with problems right away .... 1 2 3 | 4 5 6

- PLEASE TURN PAGE OVER -

1	2	3	4	5	6
strongly disagree	moderately disagree	slightly disagree	slightly agree	moderately agree	strongly agree

31. I'd do anything to feel less stressed 1 2 3 4 5 6
32. If I have any doubts about doing something, I just won't do it 1 2 3 4 5 6
33. When unpleasant memories come to me, I try to put them out of my mind 1 2 3 4 5 6
34. In this day and age people should not have to suffer 1 2 3 4 5 6
35. Others have told me that I suppress my feelings 1 2 3 4 5 6
36. I try to put off unpleasant tasks for as long as possible 1 2 3 4 5 6
37. When I am hurting, I still do what needs to be done 1 2 3 4 5 6
38. My life would be great if I never felt anxious 1 2 3 4 5 6
39. If I am starting to feel trapped, I leave the situation immediately 1 2 3 4 5 6
40. When a negative thought comes up, I immediately try to think of something else 1 2 3 4 5 6
41. It's hard for me to know what I'm feeling 1 2 3 4 5 6
42. I won't do something until I absolutely have to 1 2 3 4 5 6
43. I don't let pain and discomfort stop me from getting what I want 1 2 3 4 5 6
44. I would give up a lot not to feel bad 1 2 3 4 5 6
45. I go out of my way to avoid uncomfortable situations 1 2 3 4 5 6
46. I can numb my feelings when they are too intense 1 2 3 4 5 6
47. Why do today what you can put off until tomorrow 1 2 3 4 5 6
48. I am willing to put up with sadness to get what I want 1 2 3 4 5 6
49. Some people have told me that I "hide my head in the sand" 1 2 3 4 5 6
50. Pain always leads to suffering 1 2 3 4 5 6
51. If I am in a slightly uncomfortable situation, I try to leave right away 1 2 3 4 5 6
52. It takes me awhile to realize when I'm feeling bad 1 2 3 4 5 6
53. I continue working toward my goals even if I have doubts 1 2 3 4 5 6
54. I wish I could get rid of all of my negative emotions 1 2 3 4 5 6
55. I avoid situations if there is a chance that I'll feel nervous.......................... 1 2 3 4 5 6
56. I feel disconnected from my emotions 1 2 3 4 5 6
57. I don't let gloomy thoughts stop me from doing what I want 1 2 3 4 5 6
58. The key to a good life is never feeling any pain 1 2 3 4 5 6
59. I'm quick to leave any situation that makes me feel uneasy 1 2 3 4 5 6
60. People have told me that I'm not aware of my problems 1 2 3 4 5 6
61. I hope to live without any sadness and disappointment 1 2 3 4 5 6
62. When working on something important, I won't quit even if things get difficult 1 2 3 4 5 6

Depression items from the DASS-21

Please read each statement and select 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. I couldn’t seem to experience any positive feeling at all
2. I found it difficult to work up the initiative to do things
3. I felt that I had nothing to look forward to
4. I felt down-hearted and blue
5. I was unable to become enthusiastic about anything
6. I felt I wasn’t worth much as a person
7. I felt that life was meaningless

Liverpool Seizure Severity Scale 2.0

How many seizures have you experienced during the past 4 weeks? ___________

Note: Please enter ‘0’ if you have not experienced any seizures in the last 4 weeks and do not complete the remainder of the questionnaire. If you cannot remember the exact number of seizures you've experienced, please estimate based on the number you usually had during a single day or week.

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.

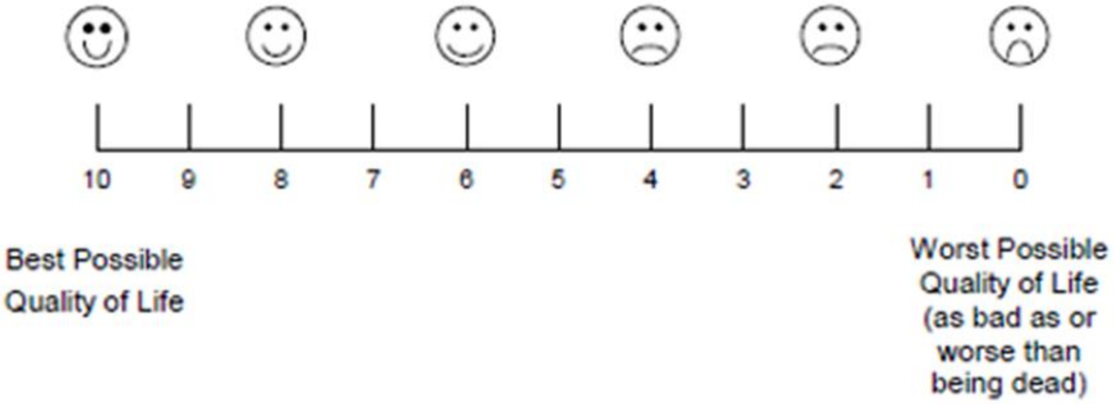
1. I feel that my most severe seizures have mostly been:	Very severe 0	Severe 1	Mild 2	Very Mild 3		
2. Most commonly when I blank out/lose consciousness:	I blank out for less than 1 minute 1	I blank out for between 1 and 2 minutes 2	I blank out for between 3 and 5 minutes 3	I blank out for more than 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

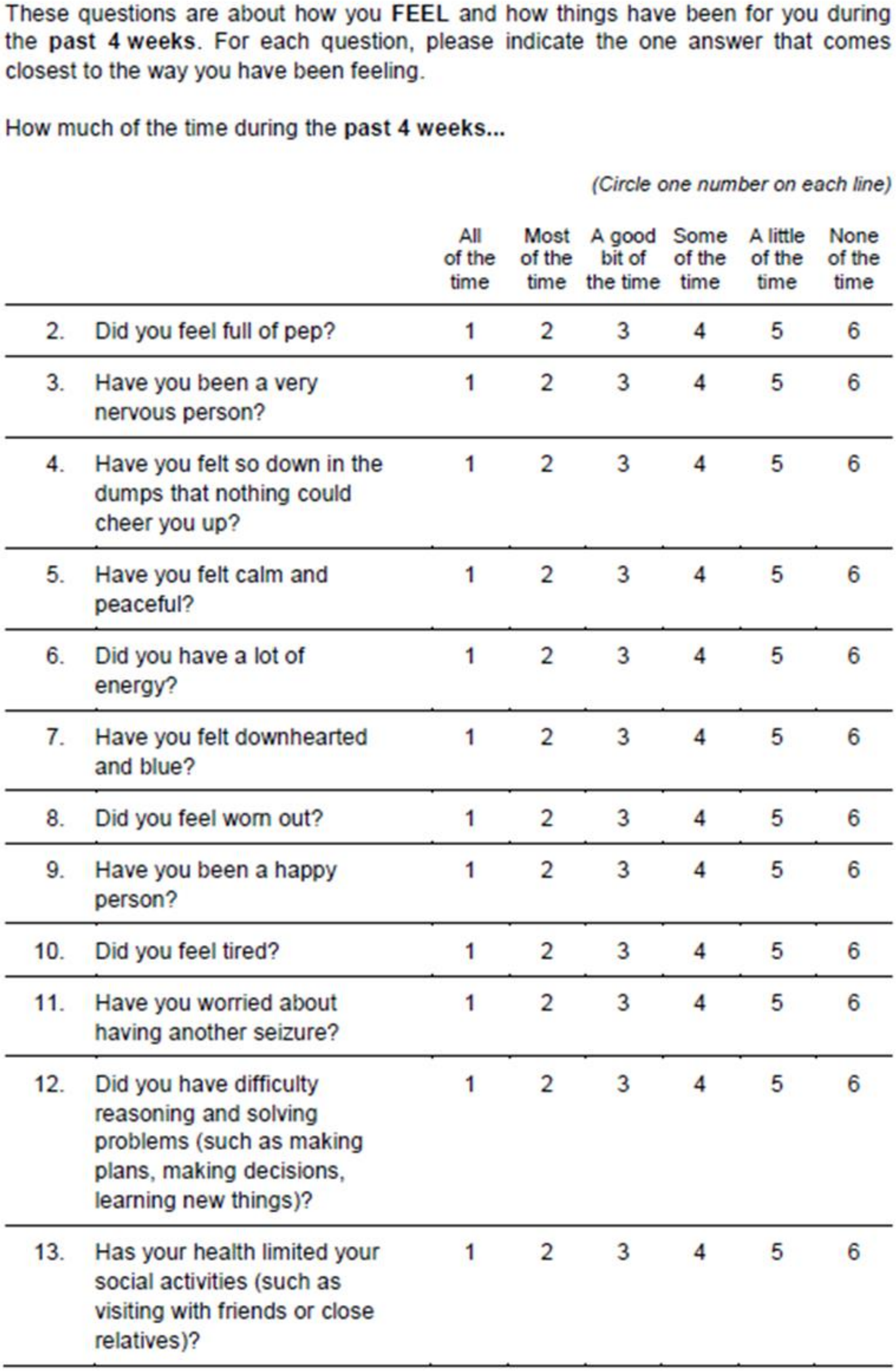
6. When I have my most severe seizures:	I always fall to the ground 0	I usually fall to the ground 1	I sometimes fall to the ground 2	I never fall to the ground 3		
7. After my most severe seizures:	I always have a headache 0	I usually have a headache 1	I sometimes have a headache 2	I never have a headache 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'm 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	

Quality of Life in Epilepsy- QOLIE 31

1. Overall, how would you rate your quality of life?

(Circle one number on the scale below)





These questions are about how you **FEEL** and how things have been for you during the **past 4 weeks**. For each question, please indicate the one answer that comes closest to the way you have been feeling.

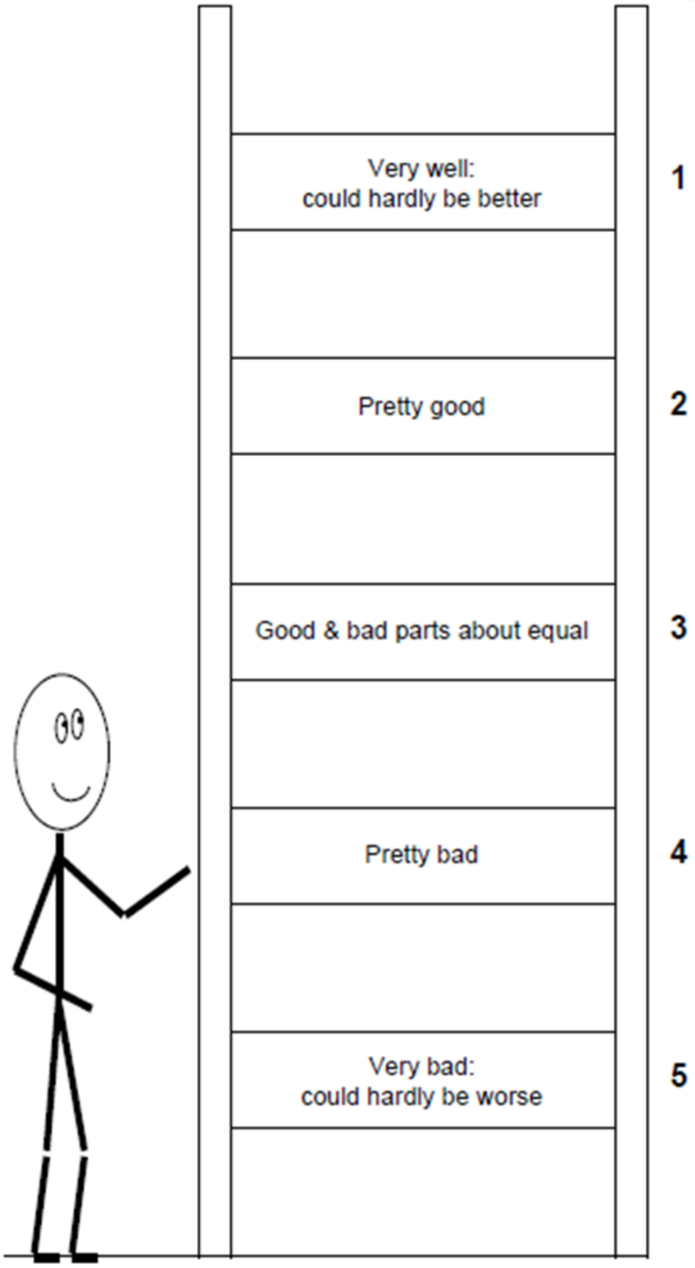
How much of the time during the **past 4 weeks...**

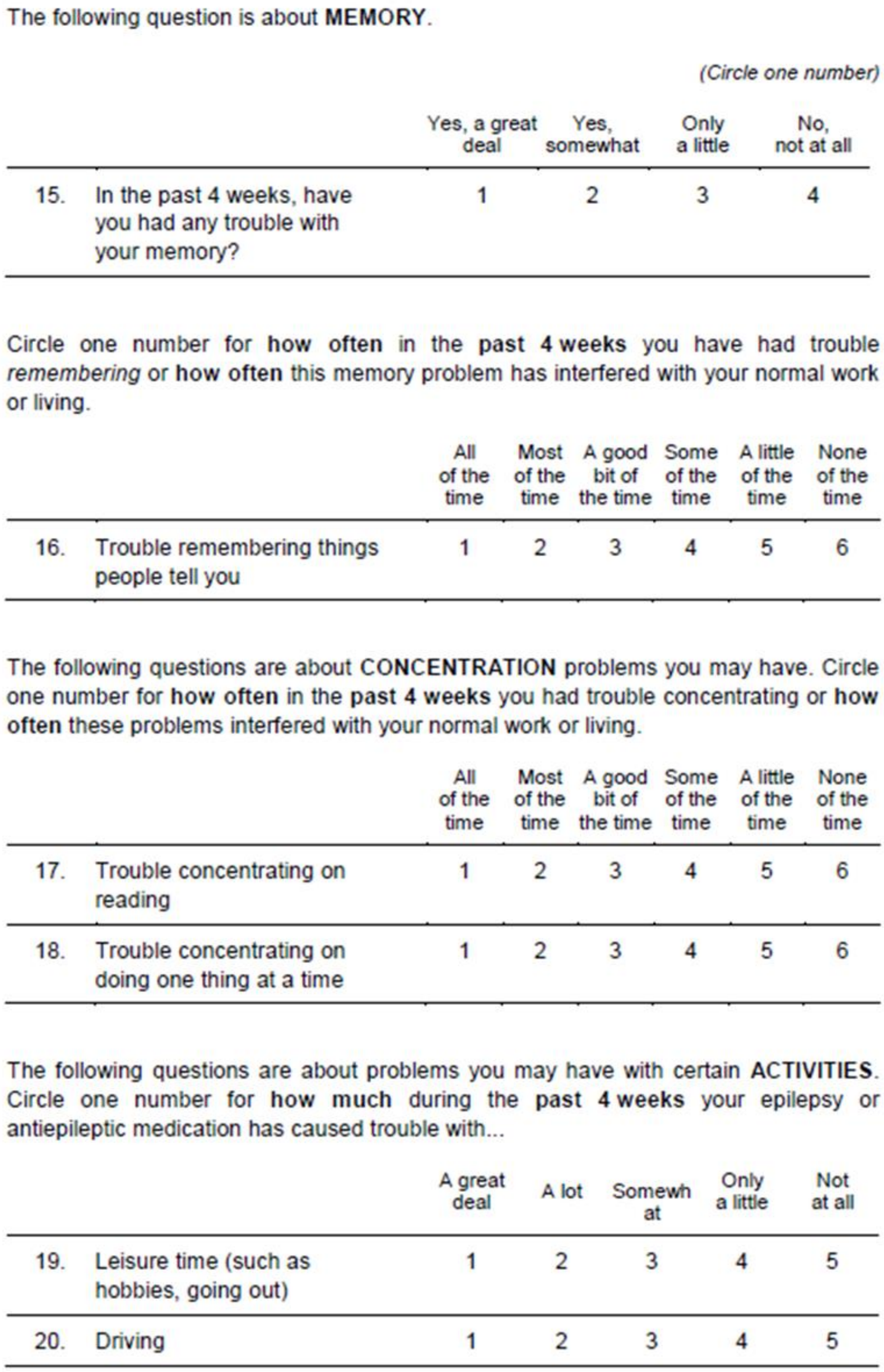
(Circle one number on each line)

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
2.	Did you feel full of pep?	1	2	3	4	5	6
3.	Have you been a very nervous person?	1	2	3	4	5	6
4.	Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
5.	Have you felt calm and peaceful?	1	2	3	4	5	6
6.	Did you have a lot of energy?	1	2	3	4	5	6
7.	Have you felt downhearted and blue?	1	2	3	4	5	6
8.	Did you feel worn out?	1	2	3	4	5	6
9.	Have you been a happy person?	1	2	3	4	5	6
10.	Did you feel tired?	1	2	3	4	5	6
11.	Have you worried about having another seizure?	1	2	3	4	5	6
12.	Did you have difficulty reasoning and solving problems (such as making plans, making decisions, learning new things)?	1	2	3	4	5	6
13.	Has your health limited your social activities (such as visiting with friends or close relatives)?	1	2	3	4	5	6

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

(Circle one number)





The following question is about **MEMORY**.

(Circle one number)

		Yes, a great deal	Yes, somewhat	Only a little	No, not at all
15.	In the past 4 weeks, have you had any trouble with your memory?	1	2	3	4

Circle one number for **how often** in the **past 4 weeks** you have had trouble *remembering* or **how often** this memory problem has interfered with your normal work or living.

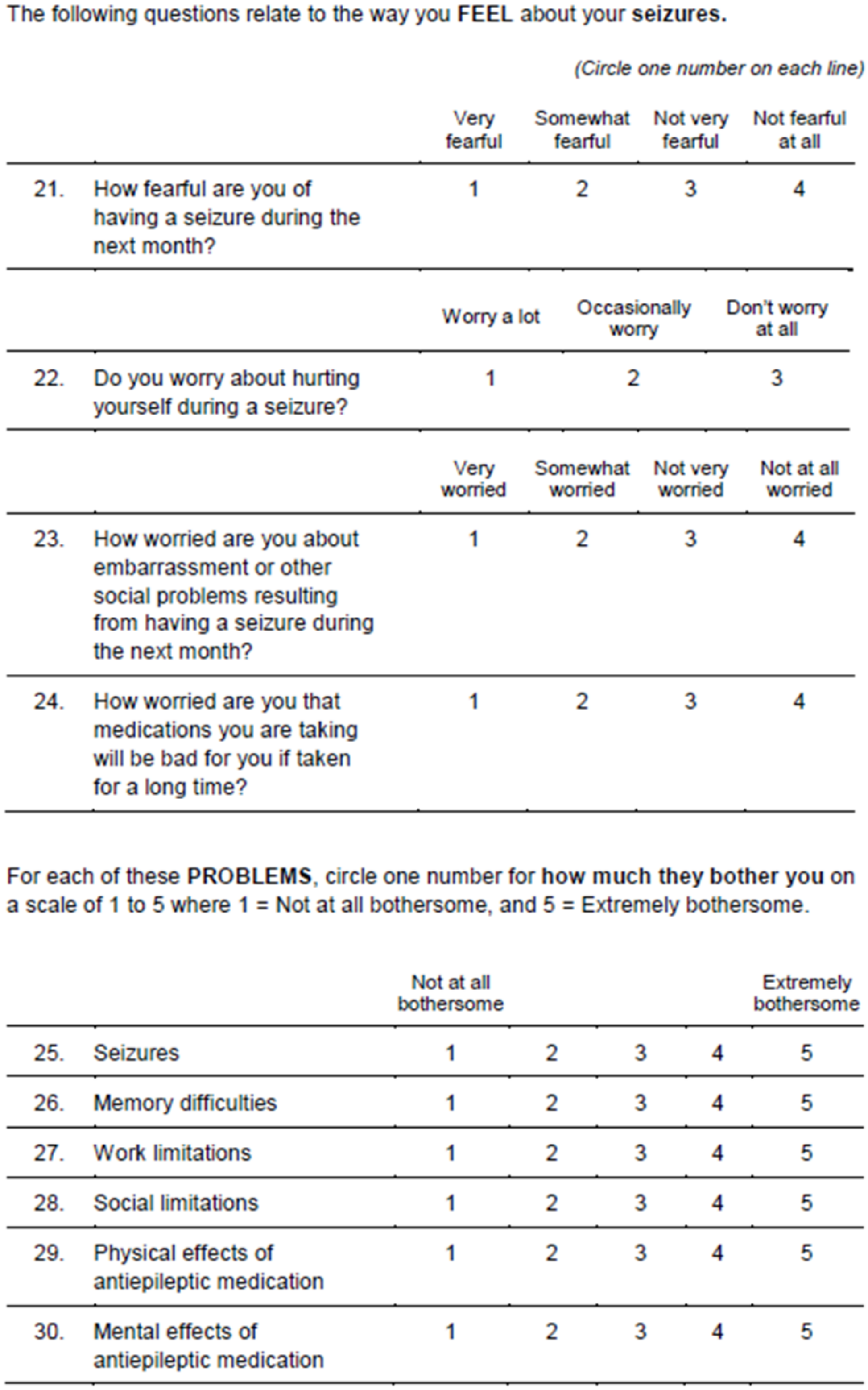
		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
16.	Trouble remembering things people tell you	1	2	3	4	5	6

The following questions are about **CONCENTRATION** problems you may have. Circle one number for **how often** in the **past 4 weeks** you had trouble concentrating or **how often** these problems interfered with your normal work or living.

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
17.	Trouble concentrating on reading	1	2	3	4	5	6
18.	Trouble concentrating on doing one thing at a time	1	2	3	4	5	6

The following questions are about problems you may have with certain **ACTIVITIES**. Circle one number for **how much** during the **past 4 weeks** your epilepsy or antiepileptic medication has caused trouble with...

		A great deal	A lot	Somewhat	Only a little	Not at all
19.	Leisure time (such as hobbies, going out)	1	2	3	4	5
20.	Driving	1	2	3	4	5



The following questions relate to the way you **FEEL** about your **seizures.**

(Circle one number on each line)

		Very fearful	Somewhat fearful	Not very fearful	Not fearful at all
21.	How fearful are you of having a seizure during the next month?	1	2	3	4

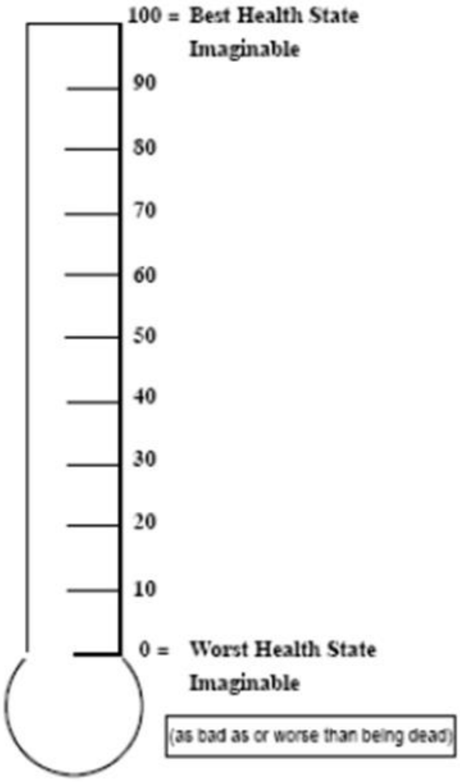
		Worry a lot	Occasionally worry	Don't worry at all
22.	Do you worry about hurting yourself during a seizure?	1	2	3

		Very worried	Somewhat worried	Not very worried	Not at all worried
23.	How worried are you about embarrassment or other social problems resulting from having a seizure during the next month?	1	2	3	4
24.	How worried are you that medications you are taking will be bad for you if taken for a long time?	1	2	3	4

For each of these **PROBLEMS**, circle one number for **how much they bother you** on a scale of 1 to 5 where 1 = Not at all bothersome, and 5 = Extremely bothersome.

		Not at all bothersome				Extremely bothersome
25.	Seizures	1	2	3	4	5
26.	Memory difficulties	1	2	3	4	5
27.	Work limitations	1	2	3	4	5
28.	Social limitations	1	2	3	4	5
29.	Physical effects of antiepileptic medication	1	2	3	4	5
30.	Mental effects of antiepileptic medication	1	2	3	4	5

31. How good or bad do you think your health is? On the thermometer scale below, the best imaginable state of health is 100 and the worst imaginable state is 0. Please indicate how you feel about your health by circling one number on the scale. **Please consider your epilepsy as part of your health when you answer this question.**

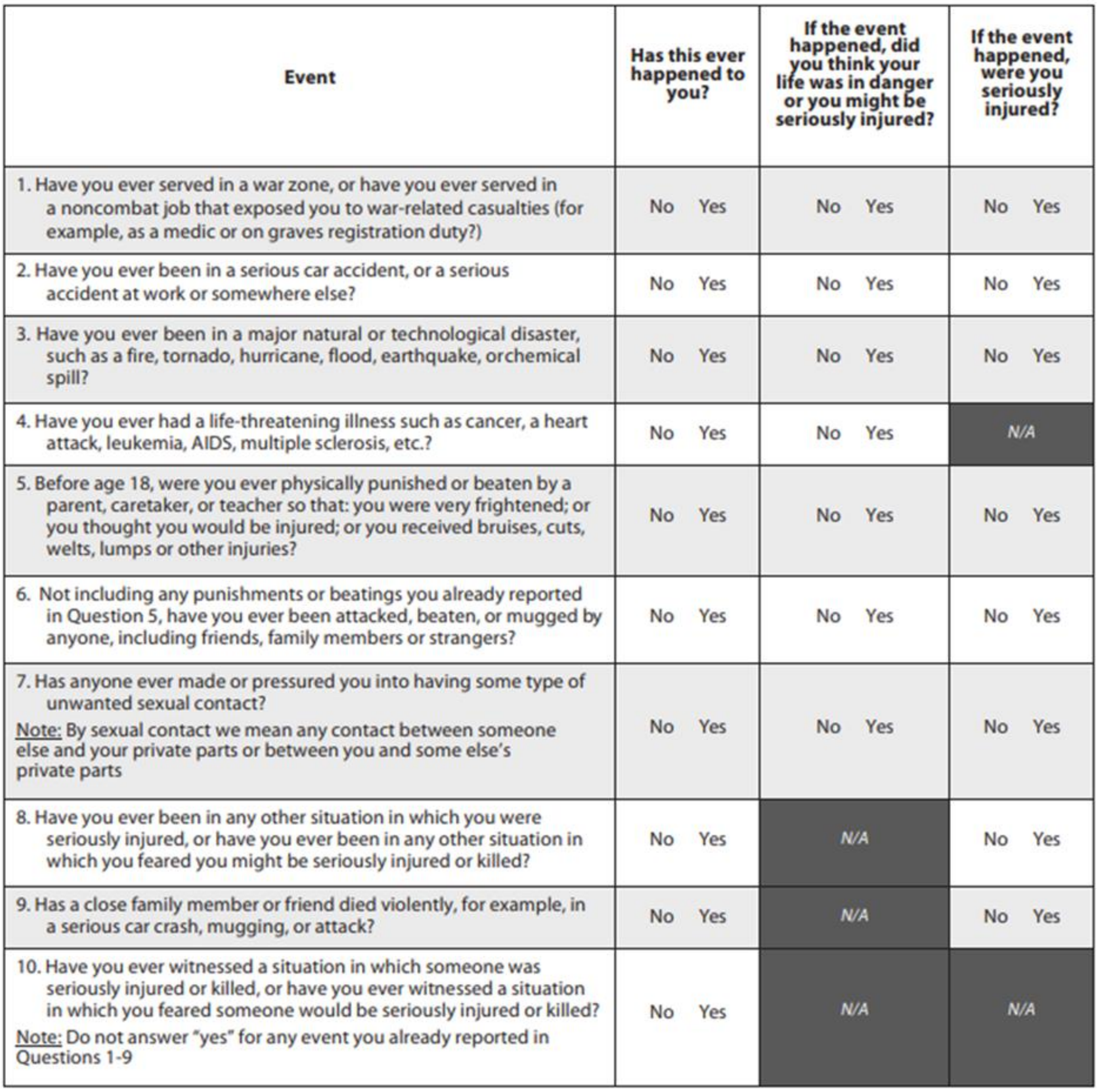


The Brief Trauma Questionnaire (BTQ)

The following questions ask about events that may be extraordinarily stressful or disturbing for almost everyone. Please select "Yes" or "No" to report what has happened to you.

If you answer "Yes" for an event, please answer any additional questions that appear to report: (1) whether you thought your life was in danger or you might be seriously injured; and (2) whether you were seriously injured.

If you answer "No" for an event, you will go on to the next event.



Event	Has this ever happened to you?	If the event happened, did you think your life was in danger or you might be seriously injured?	If the event happened, were you seriously injured?
1. Have you ever served in a war zone, or have you ever served in a noncombat job that exposed you to war-related casualties (for example, as a medic or on graves registration duty?)	No Yes	No Yes	No Yes
2. Have you ever been in a serious car accident, or a serious accident at work or somewhere else?	No Yes	No Yes	No Yes
3. Have you ever been in a major natural or technological disaster, such as a fire, tornado, hurricane, flood, earthquake, orchemical spill?	No Yes	No Yes	No Yes
4. Have you ever had a life-threatening illness such as cancer, a heart attack, leukemia, AIDS, multiple sclerosis, etc.?	No Yes	No Yes	*N/A*
5. Before age 18, were you ever physically punished or beaten by a parent, caretaker, or teacher so that: you were very frightened; or you thought you would be injured; or you received bruises, cuts, welts, lumps or other injuries?	No Yes	No Yes	No Yes
6. Not including any punishments or beatings you already reported in Question 5, have you ever been attacked, beaten, or mugged by anyone, including friends, family members or strangers?	No Yes	No Yes	No Yes
7. Has anyone ever made or pressured you into having some type of unwanted sexual contact? Note: By sexual contact we mean any contact between someone else and your private parts or between you and some else's private parts	No Yes	No Yes	No Yes
8. Have you ever been in any other situation in which you were seriously injured, or have you ever been in any other situation in which you feared you might be seriously injured or killed?	No Yes	*N/A*	No Yes
9. Has a close family member or friend died violently, for example, in a serious car crash, mugging, or attack?	No Yes	*N/A*	No Yes
10. Have you ever witnessed a situation in which someone was seriously injured or killed, or have you ever witnessed a situation in which you feared someone would be seriously injured or killed? Note: Do not answer "yes" for any event you already reported in Questions 1-9	No Yes	*N/A*	*N/A*

Debrief

Thank you for your time

Thank you for choosing to be involved in this project, your participation is greatly valued. The purpose of this study is to explore psychological factors of functional seizures and how these may impact outcomes in functional seizures. It is hoped that this study will contribute to the understanding of functional seizures and understanding of the support that could be beneficial to people who have functional seizures. A downloadable copy of the debrief form can be accessed here: Link

If you are feeling upset

If you are feeling distressed as a result of participating in this project, please contact your General Practitioner. Additionally, the following resources may be helpful:

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

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

FND Hope International
https://fndhope.org/contact/

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the lead researcher by post or email:

Megan Hawkes
Trainee Clinical Psychologist
Faculty of Health and Medicine
Lancaster University
Health Innovation One
Sir John Fisher Drive
Lancaster University
Lancaster
LA1 4AT
Email: m.hawkes@lancaster.ac.uk

Dr Fiona Eccles
Research supervisor
Faculty of Health and Medicine
Lancaster University
Health Innovation One
Sir John Fisher Drive
Lancaster University
Lancaster
LA1 4AT
Email: f.eccles@lancaster.ac.uk
Telephone: (+44) 01524 592807

Complaints

If you would like to make a complaint or concern about this study but do not wish to speak to the researcher, please contact:

Dr Ian Smith
Research Director
Doctorate in Clinical Psychology
Health Innovation One
Sir John Fisher Drive
Lancaster University
Lancaster
LA1 4AT
Phone: +44 1524 592282
Email: i.smith@lancaster.ac.uk

If you wish to speak to someone outside of the Lancaster Doctorate Programme, you may also contact:

Dr Laura Machin Tel: +44 (0)1524 594973
Chair of FHM REC Email: l.machin@lancaster.ac.uk
Faculty of Health and Medicine
(Lancaster Medical School)
Lancaster University
Lancaster
LA1 4YG

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Trauma Questionnaire Consent Form

Thank you for completing the previous questionnaires. The last questionnaire in this study is about potential traumatic or difficult experiences people can have. The following questions may be emotive, and the questionnaire is short. You will not be asked to describe any experiences and your responses will be in a Yes/No format. It is up to you whether you would like to continue and complete this questionnaire or whether you would like to skip this questionnaire and end the study (which will send us the responses for the questions you have already completed). If you do choose to continue and complete this questionnaire it may be helpful to have someone with you or to engage in some form of self-care after completing the questionnaire. Contact details for helpful resources will be provided on the debrief sheet at the end of the study.

Please select one option:

☐ Yes, I would like to continue and complete the trauma questionnaire

☐ No, I would like to skip the trauma questionnaire and end the study here

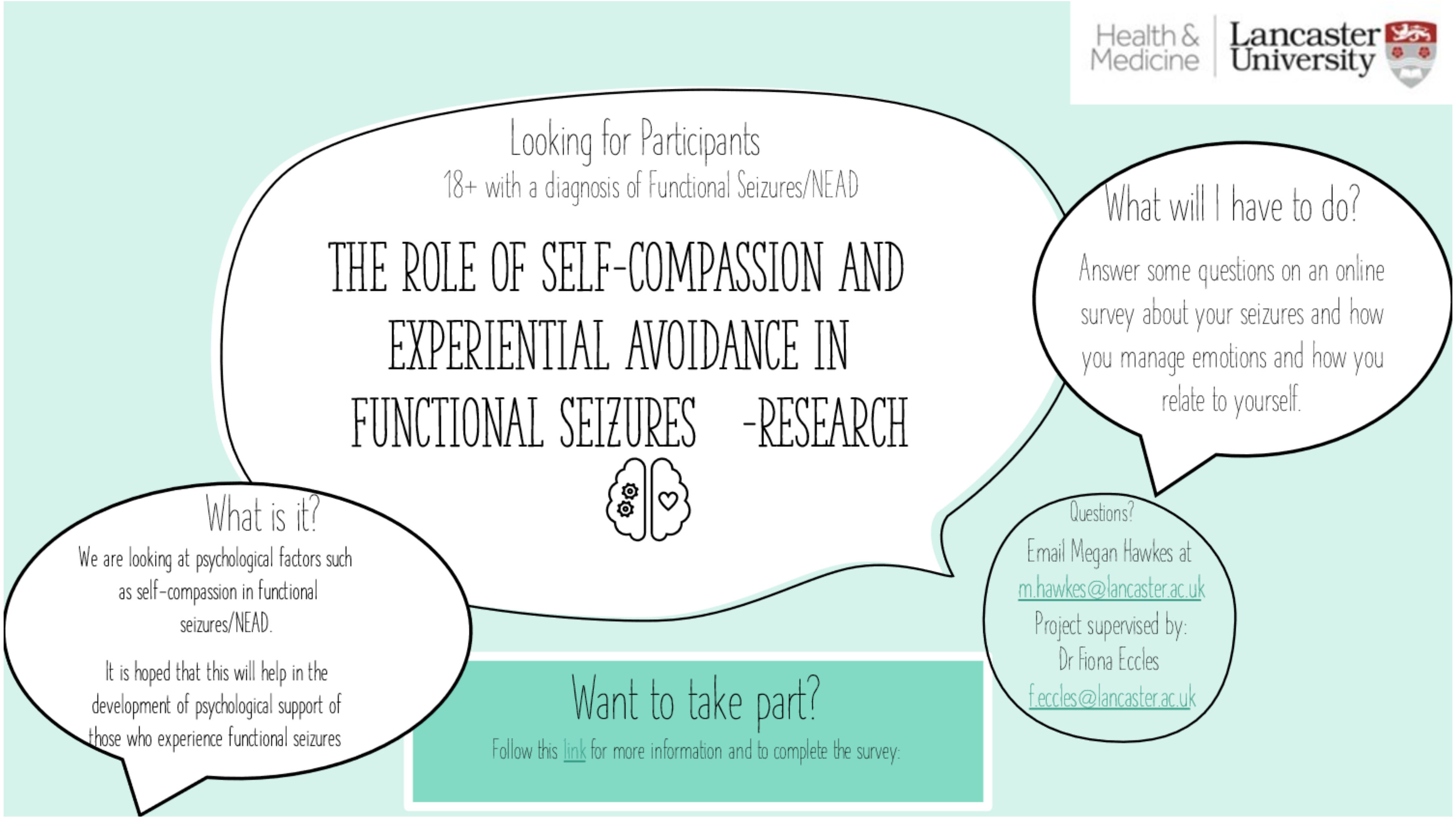
If someone selects not eligible criteria on the eligibility section

Thank you for your time. The options you have selected mean you are not eligible for this study and can now exit the study. If this was in error, please open the survey link and complete the eligibility questions again.

If someone selects ‘do not consent’ on the consent form

Thank you for your interest in the study. As you do not consent, you do not need to do anything further and can now exit the study.

Appendix 4-3 Study advert



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Looking for Participants

18+ with a diagnosis of Functional Seizures/NEAD

THE ROLE OF SELF-COMPASSION AND EXPERIENTIAL AVOIDANCE IN FUNCTIONAL SEIZURES -RESEARCH

What will I have to do?

Answer some questions on an online survey about your seizures and how you manage emotions and how you relate to yourself.

What is it?

We are looking at psychological factors such as self-compassion in functional seizures/NEAD.

It is hoped that this will help in the development of psychological support of those who experience functional seizures

Want to take part?

Follow this link for more information and to complete the survey:

Questions?

Email Megan Hawkes at
m.hawkes@lancaster.ac.uk
Project supervised by:
Dr Fiona Eccles
f.eccles@lancaster.ac.uk