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Examining the Role of Shame in Functional and Epileptic Seizures

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Declaration

I, the author, confirm that this Thesis is my own work which has not been submitted for any other degree or to any other institution.

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Lay Summary

How we feel about ourselves is influenced by how others treat us. If we are consistently treated well, we are likely to develop healthy levels of self-esteem, which is linked to self-worth and self-acceptance. Conversely, adverse experiences in childhood or discrimination, stigmatisation, or abuse later in life can lead to intense feelings of shame, which is linked to feelings of worthlessness and inferiority. Both self-esteem and shame are linked to positive and negative evaluations of the self, in comparison to others.

This thesis aimed to explore the impact of shame and self-esteem on individuals living with functional and epileptic seizures. These conditions are often stigmatised, which can adversely affect mental well-being and self-perception. Both types of seizures have similar symptoms, such as temporary loss of consciousness and involuntary movements. However, the key difference is that abnormal electrical brain activity can be observed in individuals with epilepsy, but not in those with functional seizures (FS). The exact cause of FS is still not entirely understood, but researchers theorise that it could be linked to trauma or stress response.

In this thesis, 25 research articles were reviewed to determine the factors linked to self-esteem in individuals with seizures. It's important to note that associations do not necessarily imply causation, so it's unclear whether self-esteem ‘caused’ these factors or vice versa. From a review of the literature, findings suggest that in individuals with ES, lower self-esteem was associated with feeling stigmatised, anxious, and depressed. On the other hand, high self-esteem was linked to greater knowledge about epilepsy, higher life satisfaction, better quality of life, increased self-efficacy, better community integration, and helpful coping strategies. However, we didn't observe a clear association between self-esteem, seizure frequency, or social support in people with epilepsy. Interestingly, only one article investigated self-esteem

in individuals with FS, which discovered that higher self-esteem was linked to lower seizure frequency.

In the second part of the thesis, a research study was conducted with 138 participants who had either FS or ES. The study aimed to compare the levels of shame and mental health difficulties between the two groups and to examine whether shame predicted seizures and mental health difficulties. Results showed that people with FS and ES reported high depression and somatic symptoms, but the FS group had significantly higher symptoms. People with FS had higher anxiety, but not significantly higher than ES. Findings suggested that perceived lower socioeconomic status (PSES) was associated with anxiety, depression, somatic symptoms, and seizure frequency. Interestingly, shame proneness did not provide additional information beyond PSES in explaining mental health difficulties and seizures. On the other hand, it was discovered that shame aversion, which refers to the distress one experiences due to shame, was a significant predictor of anxiety and depression, even more so than the impact of percieved socioeconomic status (PSES).

Due to the higher prevalence of depression and somatic symptoms in individuals with seizures and the impact of shame and lower socioeconomic status on mental health outcomes, comprehensive care ought to be considered for people with seizures, addressing their medical, psychological, and social needs.

Acknowledgements

Reflecting on the people who helped me in the development and completion of this project fills me with gratitude. First, I would like to thank my supervisors, Prof Markus Reuber, Dr Elizabeth Corker, and Dr Liat Levita, for their helpful guidance and feedback throughout this project. A special thanks to Stella Ogunlade for her exceptional research assistance with the systematic review. I am also thankful to all the academic and clinical tutors, and admin team at the Clinical Psychology Unit; and my placement supervisors – who were all there when I needed them. I extend my appreciation to the generous individuals at FND Hope, FND NI, FND Society, Epilepsy Action, Epilepsy Research UK, and the kind Neurologists, who provided helpful feedback on my online survey and/or helped to recruit participants. I would also like to acknowledge Torie Robinson, founder of Epilepsy Sparks, for being an inspiration by sharing her personal journey and advocating for people with epilepsy. Most importantly, I express my heartfelt appreciation to the participants who took the time to participate in this research. I hope that this research will be valuable to you.

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Abstract

Objective: This systematic review sought 1) to identify and examine research on factors associated with self-esteem in people with functional and epileptic seizures, 2) to provide a quality assessment of these studies, and 3) to make recommendations for clinical practice and future research.

Methods: Systematic searches were conducted on three databases: Scopus, PsychINFO, and Web of Science, in January 2023. Backwards and forward citation searches were carried out for the included studies. Studies meeting inclusion criteria were quality assessed prior to data extraction.

Results: Twenty-five articles were included. Most studies were cross-sectional and were of moderate quality. In people with epilepsy, factors fell into four categories: seizure-related factors, psychological factors, social factors, and 'quality and satisfaction of life' outcomes. Negative self-esteem correlates in people with epilepsy included stigma, anxiety, and depression; the positive correlates of self-esteem were knowledge about epilepsy, life satisfaction, quality of life, self-efficacy, community integration, and helpful coping styles. Studies examining the association of seizure frequency and social support with self-esteem yielded mixed findings in people with epilepsy. Only one study examined self-esteem correlates in people with functional seizures, showing a negative association between self-esteem and seizure frequency.

Conclusion: The results of this review are consistent with previous studies on self-esteem in other healthy and clinical populations. The evidence for the correlates of self-esteem in people with functional seizures is scarce. Therefore, more research is needed on the psychosocial correlates of and therapeutic intervention for self-esteem in people with functional and epileptic seizures.

Practitioner Points:

- In people with epilepsy, perceived stigma, anxiety, and depression were negative correlates of self-esteem, and the strongest positive correlates were life satisfaction, quality of life, self-efficacy, and knowledge about epilepsy. There was no clear evidence to support the association between self-esteem, seizure frequency, and social support.
- Research examining factors associated with self-esteem in people with functional seizures is scarce and, therefore, should be addressed by future research.
- Services and clinicians should consider assessing factors that can impact the self-esteem of people with seizures and provide holistic (bio-psycho-social) interventions that increase self-esteem.
- There is a need for societal-level and culture-sensitive interventions to mitigate the negative association between perceived stigma and self-esteem in people with epileptic seizures.

Keywords: self-esteem, seizure, review, adult

People with epileptic and functional seizures often experience stigma and discrimination (Akinsulore & Adewuya, 2011; Annandale et al., 2022; De Boer et al., 2008; Trinka et al., 2019) and elevated levels of mental health difficulties (Christensen et al., 2022; Diprose et al., 2016). As most studies focus on the psychopathologies and underlying vulnerabilities related to these conditions, it is pertinent also to examine factors that contribute to positive mental health and life outcomes in people with seizures. Hence, this review will set out to investigate factors that are associated with healthy self-esteem in people with functional and epileptic seizures, which have been linked to positive mental health outcomes (Orth & Robins, 2022) and resilience factors (Dale et al., 2019; Kim & Jang, 2019).

Self-esteem is the evaluation of the overall self as worthy or unworthy (Baumeister, 1998), and it refers to the extent to how much one values, approves, or likes oneself (Blaskowich & Tomaka, 1991). In addition, it refers to the affective and emotional response to self, specifically to how we *feel* about ourselves (Huitt, 2004). Several terms describe self-esteem, such as self-worth, self-regard, self-acceptance, and self-respect (Blaskowich & Tomaka, 1991).

The origins of a healthy sense of self-esteem have long been discussed in the psychological literature (Jacoby, 2016), and most psychological therapies build on the notion that our sense of self depends on our experiences with others. Thus, how we perceive and feel about ourselves is influenced by how others respond to us. From a developmental perspective, if caregivers are attuned to their child's needs and respond to them consistently, attentively, and appropriately, one could expect the child to have the basic provisions to develop healthy overall self-esteem (Jacoby, 2016). On the other hand, early life neglect and abuse can lead to experiences of excessive shame and low self-worth that one can carry throughout adulthood, contributing to various adverse mental health outcomes (Bunea et al., 2017). However, even at later developmental stages, societal (or enacted) stigmatisation and

discrimination can result in degradations of self-worth, excessive feelings of shame, and even suicidality (Carpiniello & Pinna, 2017; Oexle et al., 2017; Wood et al., 2017). This might happen through self-stigmatisation, where people internalise the perceived stigma that society holds about them (Yanos et al., 2015). Thus, it is likely that people with seizures, who receive and perceive stigmatisation by society, may be especially vulnerable to low levels of self-esteem.

Previous literature has distinguished between generic and specific self-esteem. Generic self-esteem has been proposed to encompass overall feelings regarding the self. In contrast, specific self-esteem might relate to specific aspects of the self, such as social standing, performance, appearance, and so on (Heatherton & Wyneland, 2003). Self-esteem is considered relatively stable, resulting from accumulated personal experiences (Heatherton & Wyneland, 2003). Global self-esteem is likely linked to persistent positive (or negative) evaluation by others, whereas specific self-esteem may be linked to repeatedly succeeding (or failing) at certain tasks.

It is important to differentiate the term *self-esteem* from *self-concept*, as the latter refers to the *cognitive* beliefs and information that one holds about themselves (Heatherton & Wyneland, 2003). Cognitions about the self (as reflected in the self-concept) can influence how one feels about the self (as reflected in self-esteem), but not necessarily (Blaskowich & Tomaka, 1991). For example, one may know they are an awful dancer, but that does not impact their feelings about themselves if they do not value dancing. This is in line with William James's (1892) view on self-esteem, who proposed that people's level of self-esteem depends on the extent to which they feel good about those things that matter to them.

In general terms, people with healthy levels of self-esteem are more likely to feel content with themselves, engage in more effective coping strategies in the face of adversity,

and their experiences of the social world resonate with being valued and respected (Heatherton & Wyneland, 2003). Healthy levels of self-esteem have been associated with self-efficacy, positive emotionality, attachment security, and higher work satisfaction (Orth & Robins, 2022). However, extremely high or low self-esteem has been associated with difficulties in functioning. Disproportionately high self-reported self-esteem has been linked to narcissistic tendencies (Tracy et al., 2009), which can be characterised by unconscious psychological defences to protect oneself from hidden feelings of inferiority and worthlessness (Jacoby, 2016). By contrast, low self-esteem has been associated with anxiety and depression (Orth & Robins, 2022), excessive shame (Budiarto & Helmi, 2021), self-harm (Forrester et al., 2017), loneliness and alienation (Heatherton & Wyneland, 2003).

Measuring self-esteem in individuals who experience seizures is important, as research has shown that health-related quality of life is more closely linked to mental health outcomes than seizure-related factors in those with epileptic and functional seizures (Jones et al., 2016; Rawlings et al., 2017). Additionally, studies have demonstrated that having a healthy level of self-esteem can help protect against the negative psychological and physical effects of social rejection (Beekman et al., 2017; Ford & Collins, 2010; Nezlek et al., 1997), which individuals with seizures often experience (Annandale et al., 2022; De Boer et al., 2008). Furthermore, a recent large-scale study found that self-esteem was the most significant predictor of quality of life in individuals with various mental health challenges, including anxiety, depression, personality disorders, bipolar disorder, and schizophrenia (Barbalat et al., 2022).

From the literature, it could be argued that healthy self-esteem is an underlying mechanism that contributes to general psychological well-being and quality of life. Therefore, exploring which factors improve or hinder self-esteem in people with seizures could benefit their physical and mental health outcomes. Hence, this review aims to identify,

evaluate, and present studies examining the correlates of self-esteem in people with epileptic and functional seizures.

Review Questions

1) Which factors are associated with self-esteem in people with functional and epileptic seizures?
2) How robust is the methodological quality of these studies?
3) What are the clinical and research implications of the study findings?

Methods

The protocol for this systematic review was registered on the international prospective register of systematic reviews (PROSPERO; Reference: CRD42023393416) and is available at https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42023393416

The review was completed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Page et al., 2021).

Search Strategy

A systemic literature search was conducted to identify studies from inception to 15th January 2023, using three electronic databases (SCOPUS, Medliner, PsychINFO). In addition, backwards and forward reference searches of included articles were conducted. The search syntax used for this review is displayed in Table 1.

Table 1

Research Terms Used for The Systematic Review. Studies Were Included if They Included One Research Term from Each Column (This Was Searched with 'AND'), While Any Of The Keywords Were Enough for Eligibility (This Was Searched with 'OR')

Seizure Terms	AND	Self-esteem Terms
PNES		Self-esteem
OR		OR
'Psychogenic non-epileptic'		Self-worth
OR		OR
Seizure*		Self-regard
OR		OR
Epilep*		Self-acceptance
OR		OR
'Non-epileptic attack'		Self-satisfaction
OR		OR
NEAD		Self-respect

Eligibility Criteria

Eligibility criteria were defined using the Population, Intervention, Comparison, Outcomes (PICO, Miller & Forrest, 2001) framework (Table 2). Quantitative studies were included if 1) they were available in full-text; 2) they were written in English; 3) they had a sample (≥ 16 age) of people with a diagnosis of epileptic or functional seizures; 4) they utilised a validated self-esteem measure; and 5) reported an association between any psychosocial factor and specific or generic self-esteem, with or without a comparator (control) group. Studies were excluded if they 1) used non-validated measures of self-esteem; 2) were reviews, book chapters, case studies papers/abstracts where the full report was not available 3) used a qualitative methodology. Trials examining the impact of interventions were excluded unless they also reported the levels or association between psychosocial factors and self-esteem.

Table 2

PICOS Inclusion and Exclusion Criteria

PICOS framework	Inclusion	Exclusion
Population	Adults (older than 16 years) diagnosed with epilepsy or functional seizures.	Children and adolescents (younger than 16 years). Adults with another primary diagnosis, such as brain injury, substance use etc.
Intervention	A validated self-report measure of self-esteem.	No validated measure of self-esteem or no self-report measure of self-esteem.
Comparison	Any	None
Outcomes	Any biopsychosocial outcome, such as seizure-related measures, or psychological or social outcomes.	Outcomes not named in the inclusion criteria.
Study design	Quantitative studies (e.g. cross-sectional, longitudinal, or experimental design) examining the biopsychosocial correlates of self-esteem.	Qualitative studies Reviews Case studies Book chapters Experimental studies, if did not report associations of self-esteem.

Selection Process

Articles yielded by the data search were exported into Rayyan (Ouzzani et al., 2016), a web-based systematic review software. First, the main researcher removed duplicates. After that, the researcher and a research assistant independently screened each article by title and abstract against the predetermined inclusion and exclusion criteria. Where it was unclear whether the study included correlates of self-esteem, the study was included in the full-text review to reduce the likelihood of inappropriate exclusion. On the first screening level, interrater reliability was calculated using Cohen's kappa coefficient, $k = 0.71$, indicating substantial agreement (Landis & Koch, 1977). After that, both the main researcher and research assistant independently reviewed full-text articles. On the second screening level, interrater reliability indicated moderate agreement ($k = 0.65$; Landis & Koch, 1977). Finally, the authors discussed disagreements and a consensus was met. Subsequently, the main researcher reviewed and conducted backwards and forward citation searches for the included articles.

Quality Assessment

Quality assessments were conducted using a validated tool for cross-sectional studies (AXIS, Downes et al. 2016), adapted to suit the aims of this review (Appendix A). Articles were evaluated on 15 components, which mainly included (but was not limited to): research aim, study design, sample size/power, sample representativeness, selection bias, the validity of measures, significance reporting, data analysis, methods, results, internal consistency, discussion, limitations, and ethics. Each of these components was rated as "yes", "no", or "not known" based on whether they met the criteria or not. Both the main researcher and assistant researcher independently quality-assessed articles. It has been argued that numerical quality scales can be problematic, as it is difficult to sum and weigh up the items of these checklists as a linear number, and therefore they can yield unpredictable results (Downes et al., 2016). The AXIS tool emphasises the importance of assessing each aspect of study design and providing an overall assessment of the quality of the study, which is informed by individual ratings but not simply a result of summing up the ratings of all features captured by the tool; this process, therefore, involves a degree of subjectivity (Downes et al., 2016). Hence, researchers categorised publications as high, moderate, low quality, by taking into account of individual ratings and considering the seriousness of the methodological limitation of each study (Table 3). Inter-rater agreement of the quality ratings was moderate (Cohen's kappa coefficient, k=0.53; Landis & Koch, 1977). Quality ratings of studies on which the two raters disagreed were discussed until a consensus was reached. In a study where results were unclear (Thompson & Upton, 1993), the main researcher attempted to contact authors directly and via the publisher, unsuccessfully.

Table 3

Quality Assessment Ratings of Studies

High	Articles that met 11 or more criteria and raised no methodological concerns
Moderate	Articles that met 8 or more criteria and raised some methodological concerns
Low	Articles that met fewer than 7 quality criteria and/or had major methodological issues

Data Extraction and Synthesis

For each publication, the main researcher extracted and summarised the following information: author(s), year of publication, country, study design and setting, population characteristics (including descriptive statistics), self-esteem and other relevant outcome measures, data analysis, key findings, and quality rating (Table 4). Due to the heterogeneity of the included studies, a meta-analysis was not appropriate for this review. Therefore, the main researcher conducted a narrative synthesis to address the research question. The narrative synthesis involved a thematic description and synthesis of study findings.

Results

Search Results

A PRISMA flow diagram (Page et al., 2021) describing the search and selection process is displayed in Figure 1. The initial search produced 772 articles, from which 297 were excluded as duplicates. Thereafter, the process of screening 475 articles for title and abstract identified 79 studies for full-text review. The full text of six articles could not be found, leaving 73 studies for full-text review. Fifty articles did not meet the inclusion criteria and were excluded. Ultimately, 23 articles were included in the databases. Backwards and forward searches were completed for the included

papers, leading to the inclusion of two additional articles. In total, 25 papers were included in this review for quality assessment and data extraction. Findings of the factors associated with self-esteem fell into the following categories: seizure and related variables, psychological factors, social factors, and 'quality and satisfaction of life' outcomes.

Study Characteristics

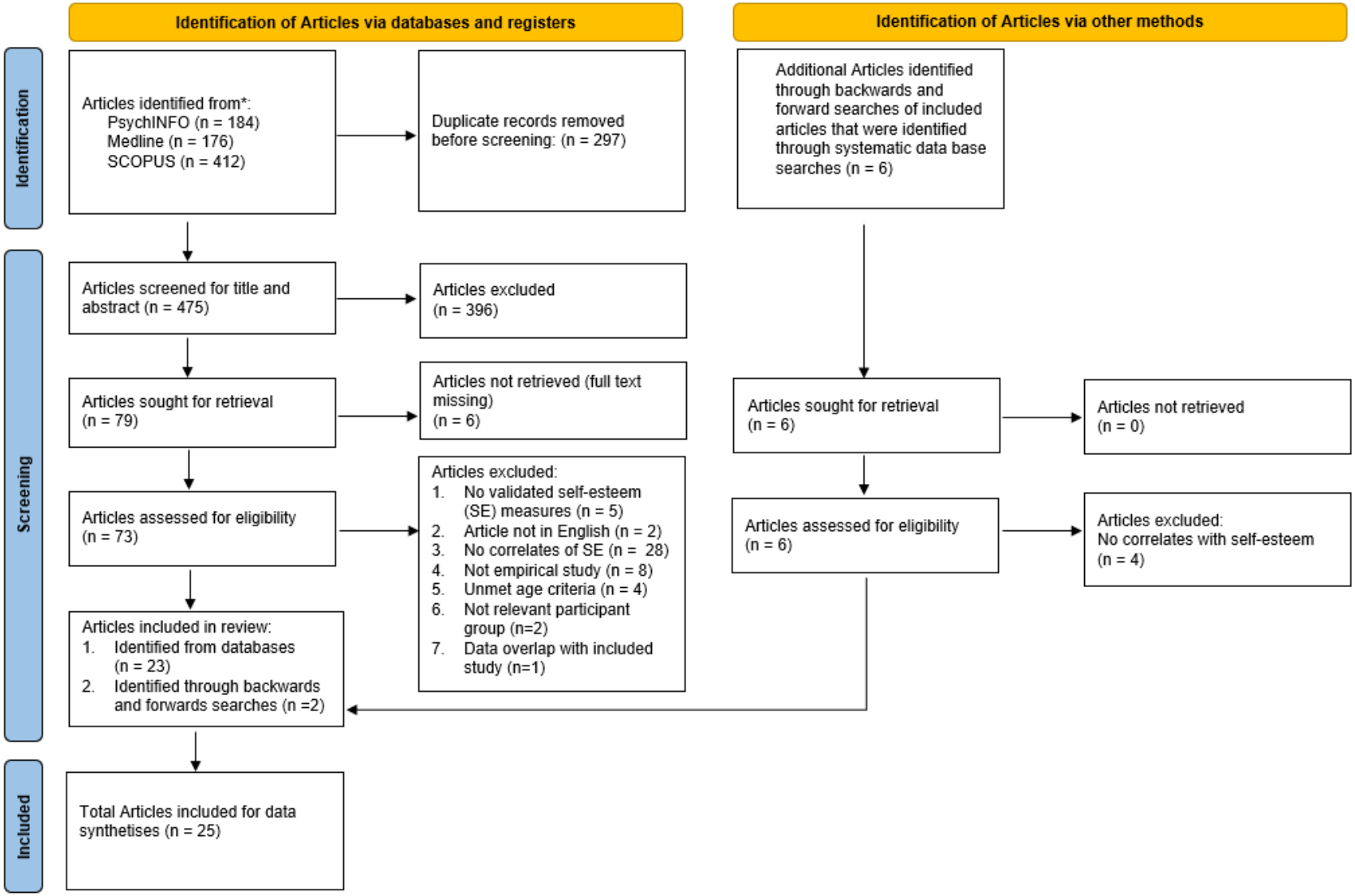
A total of 25 articles published up to 15 January 2023 were included in this review (Table 3). The articles of Lee and colleagues (2005; 2021a) shared the same data set, as well as the articles of Lee and colleagues (2016; 2018; 2021b). These were included as they reported on different aspects of the data. However, meta-analytic findings based on these studies need to be interpreted with caution in view of the overlapping data sources.

Most papers reported cross-sectional studies (k = 20), but some had longitudinal (k = 3), cohort (k = 1), or experimental (k = 1) study designs. Seventeen studies recruited participants from outpatient settings (epilepsy or neurology clinics), three through tertiary hospitals, two through online surveys, one through GPs and neurologists, one was a population-based study, and one study recruited through an epilepsy clinic and charity advertisements. The studies were international and mostly from high-income countries. The studies were conducted in: the UK (k = 5); South Korea (k = 5, with two datasets included in five studies); the US (k = 2); Brazil (k = 2); Japan (k = 1); Nigeria (k = 1); Italy (k = 1); Canada (k =1); Germany, Austria & Switzerland (k =1); New Zealand (k =1); Turkey (k =1); Sweden (k =1); Iran (k =1); Norway (k =1); and the Netherlands (k =1).

Sample sizes ranged from 25 to 409 (M =133), with a total sample size across all studies of N = 3902. Participants' mean ages ranged from 18.5 to 52.4 years; the studies included similar proportions of male and female participants (female participants ranging between 28.6-100%, with a median of 51%)

All studies included participants with epilepsy, and one study included a group with people with functional seizures, comparing it to an epilepsy group. Most studies included participants with ongoing chronic epileptic seizures. Three articles (from one dataset) reported on participants with new-onset seizures, and two articles included participants whose seizures were in remission and well-controlled with medication or surgery. Only six studies reported a sample where at least a proportion of participants had a video-electroencephalography (vEEG) confirmed diagnosis. Six studies included comparative findings between epilepsy and a healthy control group, one study compared people with epilepsy to people with functional seizures, and two compared seizure-free participants with ongoing epileptic seizures.

Figure 1
Prisma Diagram



Quality Appraisal

The quality appraisal of studies can be found in Appendix C. Most articles had clear aims (*k* = 17), appropriate study design (*k* = 24), acceptable sample size (*k* = 16), used validated measures (*k* = 22), reported significant findings clearly or adequately (*k*=14), and discussed findings appropriately (*k* = 18) including study limitations (*k* = 20). Most articles reported gaining ethics approval or consent from participants (*k* = 20). However, most studies had methodological weaknesses in terms of lack of vEEG-confirmed diagnosis, which questions the sample's representativeness (*k* = 21). The majority of studies had potential selection bias as they did not report consecutive or random sampling (*k* = 22). Furthermore, most studies did not use multivariate analysis, indicating a higher confounding risk (*k* = 14). Many studies did not describe methods or data analysis adequately (*k* = 15), or results sufficiency (*k* = 14), and had potential response bias due to not reporting attrition rates or describing nonrespondents (*k* = 22). Overall, the quality assessment suggested moderate quality (*k* = 17) for most studies included in this review. Two studies had high quality, and seven studies had poor quality (see Table 4).

Table 4

Study Characteristics

Authors, Date, & Country	**Design and Sampling frame**	**Sample Characteristics**	**Self-Esteem and Psychosocial Factor Measures**	**Data-analysis**	**Key Findings**	**Quality Rating (AXIS)**
Dilorio et al. (1994) US	Cross-sectional Epilepsy Clinic	*Epilepsy* N = 80 Mean age: 38.2 46%Female	Self-esteem (RSES) Self-efficacy (ESES) Social support (PRQ-2) Regimen-specific support (ERSSS)	Pearson's Correlations; Hierarchical Regression	SE was positively correlated with self-efficacy (r = .384***) and social support (r = 364***), but not correlated with regiment support (r = -.087). SE did not predict self-management significantly (β = .002) beyond age, self-efficacy, and regiment-specific support.	Moderate
Dimaro et al. (2015) UK	Cross-sectional Outpatient Seizure Clinic	*Epilepsy* N = 25 Mean age: 39.4 64% Female *Functional seizures* (EEG) N = 30 Mean age: 40.9 73.3% Female	Self-esteem (RSES) Anxiety (STAI)	Spearman's Rank Order Correlations	Explicit SE correlated with anxiety in the epilepsy (r_s = -.724**) and functional seizures group (r_s = -.821**). After controlling for anxiety and somatization, explicit SE was associated significantly with seizure frequency in the functional seizures group (r_s = -.71**), but not in the epilepsy group (r_s = .35).	High
Gauffin et al. (2022) Sweden	Cross-sectional Epilepsy Centre	*Epilepsy* Mean age: 26 N = 28 57.1% Female	Self-esteem (AISM) Quality of Life (QLI)	Kendall's Tau Correlations. Bayesian method	SE correlated with the total number of convulsive and focal seizures (τ = −0.43**, *BF10* = 8.8), and with quality of life (τ =0.502***; *BF10* = 1963.753)	Moderate

Habibabadi et. al. (2018) Iran	Cross-sectional Epilepsy Center	*Epilepsy* Median age: 31-35 *N* = 211 64.9% Female	Self-esteem (RSES) Social Support (SSQ)	Stepwise regression	Spouse support (β = 0.28***, ΔR^2 = .124), family member's support (β = 0.27***, ΔR^2 = .415), friend's support (β = 0.25***, ΔR^2 = .046), physician support (β = 0.20***, ΔR^2 = .047), and nurse support predicted (β = 0.26***, ΔR^2 = .168), SE changes. These variables, in total, could predict about 80% of changes in self-esteem (Adjusted R^2 = 0.81).	Poor
Hills & Baker (1992) New Zealand	Cross-sectional Epilepsy Association Members and Outpatient Clinic	*Epilepsy* Mean age: 28 *N* = 28 54% Female	Self-esteem (RSES) Epilepsy knowledge (KAEQ). Ant convulsant dosage Seizure rates Demographic questionnaire	Fisher's test	People with higher seizure-rates and low epilepsy knowledge tended to have lower self-esteem, whereas those with lower seizure rates and high epilepsy knowledge tended to have higher self-esteem (sum of probability p = 0.10*). People on high anticonvulsant dosages tended to have lower self-esteem, than people on low anticonvulsant dosages[3] (p = 0.04). Self-esteem did not correlate with seizure rates and demographics.	Poor
Kutlu et al. (2013) Turkey	Cross-sectional Epilepsy Outpatient Unit	*Epilepsy* Mean age: 29.6 *N* = 132 66.7% Female	Self-esteem (CSEI), Educational status, Disease Duration, Seizure Frequency	Unsure	Educational status was related to self-esteem (R = -0.249***), but self-esteem was not related to duration of disease (R = 0.139), age (R = 0.034), and frequency of seizures per year (R = 0.016).	Poor
Kuramochi et al. (2022) Japan	Cross-sectional Online survey	*Epilepsy* (self-reported) Mean age: 47.8 *N* = 310 38.7% Female	Self-esteem (RSES) Epilepsy Knowledge (EKS) Epilepsy Self-Stigma (ESSS)	Spearman's rank Correlation	SE significantly correlated with self-stigma (ρ = −.423***) and epilepsy knowledge (ρ = .177**), but not with seizure frequency[3].	Moderate

Lee et. al (2005)[2] South Korea	Cross-sectional Epilepsy Centers	*Epilepsy* Mean age: 32.9 *N* = 400 49% Female	Self-esteem (RSES) Stigma (SS)	Pearson's Correlations	Higher scores on the perceived stigma scale were significantly correlated with lower levels of self-esteem (*r* =- 0.31***)	Moderate
Lee et. al. (2016)[1] South Korea	Longitudinal cohort Tertiary Hospitals	*New-onset Epilepsy* Mean age: 33.2 *N* = 153 (at follow-up) 46.8% Female	Self-esteem (RSES) Stigma (SS)	Univariate analysis Multiple logistic regression	Univariate analyses showed that perceived stigma both at the time of epilepsy diagnosis[3] (*p* = 0.03) and one year later[3] (*p* = 0.04) was significantly related to self-esteem. However, multiple logistic regression analysis showed self-esteem was not a significant predictor of perceived stigma at baseline (Odds ratio 1.017; 95% *CI* 0.942–1.098) or at one year after diagnosis (Odds ratio 1.013; *CI* 0.894–1.148).	Moderate
Lee et. al. (2018)[1] South Korea	Longitudinal cohort Tertiary Hospitals	*New-onset Epilepsy* Mean age: 33.6 *N* = 98 (at follow-up) 48.2% Female	Self-esteem (RSES) Anxiety (HADAS-A) Depression (HADAS-D)	Univariate analysis Step-wise regression	SE correlated significantly with anxiety at baseline (*r* = −0.296***) and at 12 months (*r* = −0.410***), and with depression (*r* = −0.401***) at baseline and at 12 months (*r* = −0.529***). Low SE predicted higher anxiety scores at baseline and (*β* = -0.139***) at 12 months (*β* =-.289***). Low SE contributed to depression at baseline (*β* = -.270***) and at 12 months (*β*=-.517***).	Moderate
Lee (2021a)[2] South Korea	Cross-sectional Epilepsy Centers	*Epilepsy* Mean age: 32.5 *N* = 357 48.5% female	Self-esteem (RSES) HRQOL (QOLIE-31)	Hierarchical linear regression	SE accounted for 26.6% (R^2 = 0.266***) of variance in HRQOL. SE remained a significant predictor of HRQOL beyond and above various demographic, social, epilepsy-related, and psychological factors (*β* = 0.137**).	Moderate
Lee (2021b)[1] South Korea	Longitudinal cohort Tertiary Hospitals	*New-onset Epilepsy* Mean age: 33.1 *N* = 134 45.5%Female	Self-esteem (RSES) Health-related OoL (QOLIE-31)	Pearson's Correlations; Multi-variate linear regression model	SE was significantly associated with HRQoL one year after the epilepsy diagnosis in men (*r* = 0.292*), but not in women (*r* = 0.238). Self-esteem did not predict unique variance in HRQOL beyond demographic, epilepsy-related, and psychological factors.	High

May & Pfäfflin (2002) Germany Austria Switzerland	Experimental Outpatient Epilepsy Centers	*Epilepsy* Mean age: 37.5- 38.4 *N* = 242 56.6%-57.5% Female	Self-esteem (RSES) Depression (D-S)	Correlations	SE significantly negatively correlated with depression in both experimental groups (r = -0.67**).	Moderate
Onwuakagba et. al. (2020) South-East Nigeria	Cross-sectional Specialist Epilepsy Clinics	*Epilepsy* *N* = 70 Mean age: 34.9 28.6% Female	Self-esteem (RSES) Community integration (RNLI) Epilepsy Stigma (ESS)	Pearson's Correlations; Step-wise Regression	SE correlated negatively with perceived stigma ($r = -.345$***) and annual ($r = -.280$*), and six months ($r = -.267$*) seizure episodes. SE correlated positively with community integration (r = .459***), and age ($r = 0.237$*). Self-esteem did not correlate with the age of onset ($r = .149$); the one month ($r = 0.025$), one week ($r = -.146$), and the last episode of the seizures ($r = .038$). Community integration was predicted significantly by self-esteem ($R^2 = .225$***)	Moderate
Piazzini et. al (2007) Italy	Cross-sectional Epilepsy Centre	*Epilepsy: Well-controlled Seizure and Drug-Resistant Seizure groups* Mean age: 35.65 *N* = 100 50%Female	Self-esteem (FSRS) Coping style (ETC)	Pearson's Correlations Students' t-test	SE did not differ significantly between well-controlled and drug-resistant epileptic seizure groups ($t = 2.934$; $p = 0.24$). SE positively correlated with coping strategies of control ($r = .38$*) and negatively correlated with denial ($r = -.30$*) and exclusion ($r = -0.25$*). There was no correlation between SE and using social support for coping ($r = .014$). (Social support was low in both groups.)	Moderate

Poochikian-Sarkissian et.al. (2008) Canada	Cross-sectional Tertiary care centre	*Epilepsy: Seizure-free and Continued Seizure groups* Mean Age: 37.7 - 39.15 *N* = 145 55.7- 82.5% Female	Self-esteem (RSES) Self-reported seizure frequency	Students' t-test	People who were seizure-free due to medication or surgery reported significantly higher self-esteem than those with continued seizures (t = 4.86**).	Poor
Reeve & Lincoln (2002) UK	Cross-sectional Recruited through GP or Consultant Neurologist	*Epilepsy* *N* = 36 Mean age:18.5 64% Female	Self-esteem (RSES) Coping style (ACS)	Pearson's Correlations	Self-esteem correlated with non-productive coping style (r = .48**) in people with epilepsy.	Poor
Reiter et al. (2016) Norway	Population-based Norwegian Mother and Child Cohort-study	*Epilepsy* Mean age: 29.1 *N* = 409 100% Female	Self-esteem (RSES) Life-satisfaction (LS)	Univariate regression analysis	Low SE predicted overall negative life satisfaction in women with epilepsy at pregnancy weeks 15-19 (B = -7.7***), 6 months post-partum (β = −0.4***) and 18 months post-partum (β = −0.3***).	Moderate
Spector et al. (2001) UK	Cross-sectional Epilepsy Clinic	*Epilepsy* Mean age: 36.2 *N* = 100 59% Female	Self-Esteem Scale (SES) Self-Control (SCS) Anxiety (HADAS-A) Depression (HADAS-D) Internal Health Locus of Control (MHLC)	Spearman's Rank Order Correlations	SE scores were negatively correlated with anxiety (r_s = −.528***), depression (r_s = −.610***), and positively correlated with internal health locus of control scores (r_s = .303***) in people with high seizure self-control. Correlations for the low seizure controller group were not significant and not reported. The proportion of participants in the high vs low controller group was .7 to .3, respectively. High controllers and 'low controllers' did not differ in SE.	Moderate

Stuurmeijer (2001) The Netherlands	Cross-sectional Outpatient Neurology Clinic	*Epilepsy* Mean age: 38 *N* = 210 49 % Female	Self-esteem (RSES) QoL (VAS-DT)	Pearson's Correlations	Self-esteem had a significant correlation with QoL (*r* = .44***).	Moderate
Sung et. al. (2013) US	Cross-sectional Survey advertised by Epilepsy Charity	*Epilepsy* Mean age: 38.2 *N* = 270 68.9%Female	Self-esteem (RSES) Life satisfaction (SWLS) Coping style (Brief COPE) Seizure severity	Pearson's correlation	Self-esteem correlated significantly with seizure severity (*r* = -27**), positive coping (*r* = 23**), self-efficacy (*r* = 47**), and life satisfaction (*r* = .64**). Self-esteem (*β* =.563**; 95% *CI* [.457, .669]) and self-efficacy mediated the relationship between seizure severity and life satisfaction.	Moderate
Tedrus & Marti (2022) Brazil	Cross-sectional Outpatient Neurology Clinic	*Epilepsy*: *TLE-HS and other epilepsy groups* Mean age: 46.1- 48.5 *N* = 86 44.7-56.2% Female	Self-esteem (RSES) Religiousness/ Spirituality (BMMRS) HROoL (QOLIE-31)	Network analysis (Fruchterman-Reingold algorithm)	There was a low correlation between religiousness/spirituality, HRQoL and self-esteem[3] for both epilepsy groups (TLE-HS and other epilepsies) and per epilepsy group alone[3]. There was no correlation between SE and religious spirituality in any groups.	Moderate
Tedrus & Lange (2021) Brazil	Cross-sectional Outpatient Neurology Clinic	*Epilepsy* *N* = 71 Mean age: 52.4 49.2-60%Female	Self-esteem (RSES) Subjective memory loss (MAC-Q)	Student t-test	People who reported high subjective memory loss (MAC-Q ≥ 25) had significantly lower self-esteem [4] (*p* = .035) compared to those with low subjective memory loss (MaC-Q < 25) in the epilepsy group.	Poor

Upton (1993) UK	Cross-sectional; National Epilepsy Assessment Centre	*Epilepsy* Mean age: 30.1 *N* = 65 35.4% Female	Self-esteem (RSES) Perceived Family and Friends Support (PSS-FA; PSS-FR) Age Marital Status Seizure frequency Seizure duration Structural & Practical Support (SOS)	Kendall's Tau Correlations Mann-Whitney	SE correlated with perceived support from family (τ_b = .262**) and perceived support from friends (τ_b = .227**), and age (τ_b = 0.132*). There was no relationship between SE and seizure frequency and duration; marital status (z = -.23, p = .82); number of friends[3]; or professional[3] or practical support[3].	Moderate
Upton & Thompson (1992) UK	Cross-sectional Epilepsy Centre	*Epilepsy* Mean age: 30.42 *N* = 137 38% Females	Self-esteem (RSES) Coping style (WCC)	Kendall's Tau Correlations, Hierarchical Multiple Regression	Self-blame (τ = .179*) and wish-fulfilment coping strategies (τ = .220*) were associated with lower levels of self-esteem. No significant relationship were found between self-esteem and congnitive restructuring (τ = -.016), threat minimization (τ = -.055), emotional expression (τ = .055), and information seeking (τ = .058). And coping styles of wish-fulfilment fantasy (B = 0.42***), cognitive restructuring (B = -0.23*), self-blame (B = 0.23*), and number of drugs being taken (B = 0.17*), and predicted self-esteem and accounted for 26.76% of the variance.	Poor

Note. RSES = Rosenberg Self-Esteem Scale; ESES =The Epilepsy Self-Efficacy Scale; PRQ-2 =The Personal Resource Questionnaire Part 2; ERSSS = The Epilepsy Regiment-Specific Support; STAI = Spielberger State–Trait Anxiety Inventory= AISM= "As I see me"; QLI = Quality of Life Index; HADS = Hospital Anxiety and Depression Scale; KAEQ = Knowledge about Epilepsy Questionnaire; SSQ = Northouse Social Support Questionnaire; EKS = Epilepsy Knowledge Scale; ESSS = Epilepsy Self-Stigma Scale; SS= Stigma Scale; HADAS-A = Hospital Anxiety Depression Scale - Anxiety; HADAS-D= Hospital Anxiety Depression Scale – Depression; HRQOL= Health-related Quality of Life; QOLIE-31= Quality of Life in Epilepsy Inventory-31; D-S = Depressive Mood Scale; RNLI = Reintegration to Normal Living Index; ESS = Epilepsy Stigma Scale; FSRS = Forsman's Self-esteem Rating Scale; ACS= Adolescent Coping Scale; ETC = Echelle Toulousaine de Coping; LS= 5-item Satisfaction with Life Scale; SES = Self-Esteem Scale; MHLC = The Multi-Dimensional Health Locus of Control; SCS; Self-Control Schedule= VAS-DT= visual analogue scale with "delighted-terrible faces" of quality of life; SWLS = Satisfaction with Life Scale; TLHE-H = Temporal lobe epilepsy with hippocampal sclerosis; BMMRS = Brief multidimensional measure of religiousness/spirituality; PSS-FA = Perceived Social Support Family; PSS-FR= Perceived Social Support Friends; SOS = Significant Other's Scale; WCC = The ways of coping checklist; CSEI = Copersmith Self-Esteem Inventory; MAC-Q = Memory Complaint Questionnaire;

[1] Data identical to Lee (2016) article

[2] Data identical to Lee (2005) article

[3] Precise magnitude of association was not reported in the original study

[4] Test-statistic and/or effect size was not reported

* p<0.5= ** p<0.01= *** p<0.001;

Narrative Synthesis

The summary of findings is displayed in Table 4. In the section below thematic summary and synthesis of study findings are described. Seizure-free participants refer to people diagnosed with epilepsy, who were seizure-free in the last two years.

Self-esteem Measures

The most frequent measure of self-esteem was the Rosenberg Self-esteem Scale (RSES; *N* = 21). Other studies utilised the 'As I see me' questionnaire (AISM; *N* = 1), Forsman's Self-esteem Rating Scale (FSRS; *N* = 1), Coopersmith Self-Esteem Inventory (CSEI; *N* = 1), and the Self-esteem Scale (SES; *N* = 1).

Functional Seizures: Factors Associated With Self-Esteem

Only one study examined self-esteem correlates in people with functional seizures (Dimaro et al., 2015). This study found a strong negative correlation between explicit self-esteem and anxiety. Furthermore, after controlling for anxiety and somatization, explicit self-esteem was negatively associated with seizure frequency in the functional seizures group but not the epilepsy group.

Epileptic Seizures: Factors Associated With Self-Esteem

Most studies measured the correlation between self-esteem and seizure-related variables (*N* = 11) and psychological factors (*N* = 11). Other studies reported on the association between self-esteem and social factors (*N* = 7), and 'quality and satisfaction of life' outcomes (*N* = 6). The following section will discuss these results, starting with the most frequently reported outcomes.

Seizures and Related Factors. The section below describes findings related to seizures, such as seizure frequency, seizure severity and duration, epilepsy knowledge, age of seizure onset, anticonvulsant dosage, and memory loss.

Seizure Frequency. The association between seizure frequency and self-esteem was

measured in eight studies. These studies yielded mixed results, and no clear association between self-esteem and seizure frequency could be established. One study reported a negative correlation between self-esteem and the total number of focal and convulsive seizures (Gauffin et al., 2020). Another found that people with higher seizure rates had lower self-esteem than those with higher seizure rates (Hills & Baker, 1992). However, three studies found no association between self-esteem and seizure frequency (Kutlu, 2013; Kuramochi et al., 2022; Upton, 1993). In addition, another study found that self-esteem correlated negatively with the number of six-month and annual episodes of seizures but was not correlated with more recent episodes, such as one week, one month, and the last seizure (Onwuakagba et al., 2020).

Comparative studies also had contrasting results. For example, one study found that seizure-free people had higher self-esteem than those with continued seizures (Poochikian-Sarkissian et al., 2008). However, another study did not find differences between those who were seizure-free compared to those with uncontrolled seizures (Piazzini, 2007). Another study reported that, after controlling for anxiety and somatisation, there was no association between self-esteem and seizure frequency in those with epilepsy. However, such an association was found in a functional seizure group (Dimaro, 2020).

Seizure Severity and Duration. Self-esteem was negatively correlated with seizure severity (Sung et al., 2013) and seizure duration (Upton, 1993). However, in a study with very poor methodological quality, self-esteem was not related to the duration of epilepsy (Kutlu, 2013).

Epilepsy Knowledge. Two studies indicated that knowledge about epilepsy was positively associated with self-esteem (Hills & Baker, 1992; Kuramochi et al., 2022).

Age of Seizure Onset. There was no evidence for correlations between self-esteem

and the age of seizure onset (Onwuakangba et al., 2020).

Anticonvulsant Dosage. People with epilepsy who were on high anticonvulsant dosages tended to have low self-esteem, whereas people on low anticonvulsant dosages tended to have high self-esteem (Hills & Baker, 1992).

Memory Loss. Those with epilepsy who reported high subjective memory loss had lower self-esteem than those with low subjective memory loss (Tedrus & Lange, 2021). This study also reported higher objective memory loss in people with seizures, than in the control group.

Psychological Outcomes. The second below describes factors related to psychological outcomes, such as anxiety and depression, coping styles, self-efficacy, religious spirituality, and age.

Anxiety and Depression. There was a significant negative correlation between self-esteem and anxiety, and depression, as shown by four studies. A longitudinal study found that low self-esteem predicted higher anxiety and depression in people with newly diagnosed epilepsy at the time of the diagnosis as well as 12 months later (Lee, 2018). Supporting the above findings, anxiety (Dimaro et al., 2015) and depression (May & Pfaffin, 2002) were associated in people with epilepsy, regardless of the length of time since their diagnosis. Finally, one study found that anxiety and depression negatively correlated with self-esteem in people with epilepsy with a high internal locus of control but not in people with a low internal locus of control (ILOC; Spector, 2001). In this latter study, non-significant findings in the low-internal locus group could be explained by the significantly fewer participants in that group, which could have interfered with detecting an effect.

Coping Styles. Helpful coping styles seemed to have a positive association with self-esteem, whereas unhelpful coping styles showed a negative association. For example, Piazzini et al. (2007) found that self-esteem was positively correlated with coping strategies

of ‘control’ (referring to coping by organising and problem-solving) and negatively associated with ‘denial’ (coping by refusal to acknowledge problems) and ‘exclusion’ (coping by detachment and avoidance). Similarly, Sung et al. (2013) found that self-esteem correlated with positive coping, which referred to adaptive coping strategies characterised by acceptance, planning, positive reframing, and using instrumental support.

The findings of two papers suggest unexpected findings that may to be linked to erroneous reporting of authors. One paper (Reeve & Lincoln, 2002) reported in their results table that self-esteem was positively correlated with a non-productive coping style in people with epilepsy. However, there was no reporting or discussion of this statistical finding in the article’s main text. Another study (Thompson & Upton, 1993), reported in the main text of their article, that coping strategies such as wish-fulfillment (meaning the indulging in the longing for the illness to go away by fantasies of escapisim) and self-blame were associated with lower self-esteem. However, the statistical findings they reported in the study tables suggest the opposite. The authors of this article made incorrect interpretations of statistical results about other study outcomes as well, raising concerns about the statistical robustness and reliability of their study. Therefore, reliable conclusions cannot be drawn from this article in terms of associates of self-esteem.

Self-efficacy. There was a positive correlation between self-efficacy and self-esteem, as shown by two studies (Dilorio et al., 1994; Sung et al., 2013).

Religious spirituality. There was no correlation between self-esteem and religious spirituality. This was indicated by network analyses showing no association between religiousness, health-related quality of life, and self-esteem for people with temporal lobe epilepsy with hippocampal sclerosis and other types of epilepsy (Tedrus & Marti, 2022).

Age. There was some evidence indicating that self-esteem increases with age. Two studies with moderate methodological qualities found a positive correlation between self-

esteem and age (Onwuakangba et al., 2020; Upton, 1993). However, one study indicated no correlation between self-esteem and age (Kutlu, 2013), which may be due to the extremely weak methodology of this study. Another study with weak methodology indicated no relationship between self-esteem and demographics (Hills & Baker, 1992), but they did not specify how they measured demographics and what that involved.

Social Factors. Please see below factors that are related to social factors, such as stigma, social support, and community integration.

Stigma. *S*elf-esteem significantly negatively correlated with perceived stigma (Lee et al., 2005; Lee et al., 2016; Onwuakagba et al., 2020) and self-stigma (Kuramochi et al., 2022), as indicated by four studies using univariate analyses. In the study of Lee et al. (2016), univariate analyses showed that perceived stigma significantly negatively correlated with self-esteem at the time of epilepsy diagnosis and one year later. However, using multiple logistic regression, they found that self-esteem was not a predictor of perceived stigma at the time of diagnosis and one year later. This may be explained by the observation that 13% of the sample felt less stigmatised a year after receiving their diagnosis.

Social Support. There was no clear association between social support and self-esteem. For example, Piazzini et al. (2007) found that people with epilepsy who were seizure-free or had drug-resistant seizures did not often use social support as a coping strategy, and their self-esteem was not associated with coping by using social support. On the contrary, two studies with weak methodologies found that self-esteem was positively associated with social support (Habibabadi, 2020; Upton, 1993). One of these found a positive correlation between self-esteem and support from family and friends, but not with marital status, number of friends, and professional or practical support (Upton, 1993). The other found that spouse, family member, friend, physician, and nurse support predicted

12.4%, 41.5%, 4.6%, 4.7%, and 16.8% of self-esteem changes, respectively (Habibabadi, 2020).

Community Integration. Self-esteem was positively correlated with community integration (as measured by Reintegration to Normal Living Index) and explained 22.5% of the variance in community integration, as indicated by the study of Onwuakagba et al. (2020).

Quality and Satisfaction of Life. Please see below the factors that are related to life quality and life satisfaction.

Life Satisfaction. Self-esteem was positively associated with life satisfaction, as indicated by two studies. Sung et al. (2013) found that self-esteem positively correlated with life satisfaction; moreover, self-esteem mediated the relationship between seizure severity and life satisfaction. This is in line with the longitudinal study of Reiter et al. (2016), who found, using regression analyses, that low self-esteem predicted overall negative life satisfaction in women with epilepsy at pregnancy weeks 15-19, 6 months post-partum, and 18 months post-partum.

Quality of Life. Self-esteem was associated with QoL. Two studies using different self-esteem (RSES; AISM) and quality life (visual analogue, QoL) measures found that self-esteem positively correlated with quality of life (Gauffin et al., 2020; Stuurmeijer et al., 2001). Similarly, Lee et al. (2021a) found that high self-esteem (RSES) accounted for a 26.6% variance in health-related QoL, predicting unique variance beyond various demographic, social, epilepsy-related, and psychological factors. However, in people with new onset epilepsy, self-esteem was only positively associated with health-related QoL in men, and it did not explain unique variance beyond other measures (Lee et al., 2021b)

Discussion

The current systematic review sought to identify, evaluate, and present findings on the associations of self-esteem in people with epileptic or functional seizures. The factors associated with self-esteem and the clinical and research implications will be discussed while also considering limitations.

Key Findings in Individuals with Epilepsy

The most frequently reported and unanimous finding across the included studies in this review was the negative associations between self-esteem and perceived stigma in people with epilepsy. Furthermore, several studies showed a negative association between self-esteem, anxiety, and depression. In terms of positive correlates, self-esteem was associated with greater knowledge about epilepsy, more life satisfaction, quality of life, self-efficacy, age, and community integration. Helpful coping styles were positively associated with self-esteem, whereas unhelpful coping styles showed a negative association. Many studies examined the relationship between seizure frequency and self-esteem and social support and self-esteem, but no clear association existed between these constructs. There was some preliminary evidence that high anticonvulsant dosages, subjective memory loss, seizure severity, and duration may be negatively associated with self-esteem. However, more research is needed to disentangle the main and moderating effects of these associations. Finally, studies showed no relationship between self-esteem and seizure onset or religious spirituality.

The finding that lower self-esteem is associated with perceived stigma in people with epilepsy is based on international samples, including those captured in studies from South Korea, Japan, and Nigeria. Similar to the present findings, felt or perceived stigma has been negatively associated with self-esteem in various international and clinical populations, including people with cancer (Huang et al., 2021) and various other health

conditions (Van Brakel, 2006), learning disabilities (Haft et al., 2023), and mental health difficulties (Livingston & Boyd, 2010). Since stigma is commonly experienced and perceived by people with epilepsy worldwide and is associated with an increased risk of psychological difficulties and impaired quality of life (Kwon et al., 2022), stigma might threaten the self-esteem of people with ES. Equally, low self-esteem might make people more vulnerable to feeling stigmatised; however, such a hypothesis should only be tested if also controlling for societal (enacted) stigmatisation to prevent putting the blame on the person.

This review's findings show that low self-esteem is associated with anxiety and depression in people with ES, which is in line with results in other clinical populations (Orth & Robins, 2022). As stigma is associated with mental health difficulties, and self-esteem is negatively related to both, it is possible that self-esteem could mitigate the association between mental health difficulties and stigma. This was suggested by a recent meta-analysis that found that self-esteem can function as a protective factor between self-stigma (referring to the perceived stigma that the person internalised) and depression (Nan et al., 2023). Moreover, a meta-analysis of longitudinal studies indicated that the effect of self-esteem on depression was significantly stronger than that of depression on self-esteem, and self-esteem predicted anxiety slightly more strongly than anxiety predicted self-esteem (Sowislo & Orth, 2013). In addition, as per a longitudinal study cited in this review (Lee, 2018), low self-esteem was associated with anxiety and depression at the time of receiving an epilepsy diagnosis, and even after a year. These findings suggest that healthy self-esteem may help buffer against self-stigma and related mental health difficulties in people with ES. On the other hand, low self-esteem may make people more vulnerable to developing psychopathologies, such as depression and anxiety.

The findings of this review suggest that higher self-esteem is correlated with higher

life satisfaction and higher quality of life in people with epilepsy. This suggests that self-esteem may have an important interconnected role in life satisfaction and quality of life, as further supported by other studies on people with various mental health difficulties (Barbalat et al., 2022).

In line with previous studies (Orth & Robins, 2022), our findings indicated a positive association between self-esteem, knowledge about epilepsy, and self-efficacy. Thus, it is worth considering whether increasing people's knowledge about their seizures could result in them becoming better able to cope with or accept seizures, thereby increasing their self-esteem and perhaps their self-efficacy. Alternatively, it is possible that individuals with higher self-esteem have greater self-efficacy (as found by Sung et al., 2013) and are more capable of seeking and obtaining knowledge about epilepsy.

Self-esteem and self-efficacy may also be linked to a person's coping style. More helpful coping styles (such as positive and control-driven coping) were found to have positive associations with self-esteem. In contrast, unhelpful coping styles (such as denial or exclusion) had negative associations. These findings further support the notion that a person's positive feelings towards the self, as reflected in their self-esteem, may be key to coping with daily life and adversities (Barbalat et al., 2022).

Previous research has also associated higher self-esteem with a greater ability to pursue beneficial relationships (Marshall et al., 2014; Heatherton & Wyneland, 2003). However, social support was not often used as a coping strategy in people with seizures, as indicated by one study (Piazzini et al., 2007). Furthermore, there were no clear associations between self-esteem and the use of social support across the studies in this review. On the other hand, previous research shows that social support contributes to lower mortality rates and positive mental health outcomes (Holt-Lunstad et al., 2010) and that self-esteem can moderate the relationship between social support and health outcomes (Lee & Way, 2019).

This suggests that those with lower self-esteem might not be able to utilise social support easily or that social support is less available for them. Thus, the mixed findings of this review on the correlations between self-esteem and social support could be related to the generally lower levels of self-esteem in the study samples.

On the other hand, better community integration was associated with higher self-esteem in one study. Whilst there are no other studies, to the author's knowledge, that examine the relationship between self-esteem and community integration, it would not be surprising if community integration played a significant role in people's self-esteem. Since people with epilepsy often feel stigmatised and discriminated against in society, community integration might be a key factor that can help people feel valued and respected by others, contributing to feelings of self-worth, in line with a social constructivist view of mental health (Walker, 2006).

This review found preliminary evidence that seizure severity and duration correlated negatively with self-esteem. However, there were mixed findings regarding the association between self-esteem and seizure frequency. This may be explained by the fact that studies measured seizure frequency in various ways or with tools that were not described in detail or validated. Furthermore, it may be difficult for participants to accurately recall the frequency of their seizures over longer periods of time in retrospect, leading to inaccuracies in reporting, and, thereby, inconsistent scores on outcome measures.

Key Findings in Individuals with Functional Seizures

Only one study examined correlates of self-esteem in people with functional seizures (Dimaro et al., 2015). This study found lower self-esteem in people with functional seizures than in those with epileptic seizures. Given the high prevalence of trauma in this population, it was suggested that this might be associated with childhood trauma rather than stigma alone in people with functional seizures. Furthermore, this study found that after controlling

for anxiety and somatisation, explicit self-esteem was negatively associated with seizure frequency in the functional seizure group but not in the epilepsy group. Hence, Dimaro et al. (2015) proposed that low self-esteem may contribute to the maintenance of functional seizures and mediates the relationship between attachment and psychopathology.

Strengths and Limitations

The current review has a number of strengths and limitations. One of the limitations is that most studies had a cross-sectional design, except for one study that used a mother and child cohort design and three studies from the same data utilising longitudinal design. Unlike longitudinal and cohort studies, cross-sectional studies simultaneously measure predictor and dependent variables; therefore, they cannot establish causal relationships between self-esteem and other factors.

Most included studies used convenience sampling and did not confirm the diagnosis of participants by vEEG. This may have contributed to sampling and representation bias in this review. The majority of studies recruited participants from Epilepsy Clinics, where highly qualified professionals made diagnostic decisions. However, 25-30% of people previously diagnosed with epilepsy who do not respond to drug treatment do not have epilepsy (Amin & Benbadis, 2019). Therefore, diagnostic assessments incorporating EEG remain essential to avoid complications resulting from a missed differential diagnosis (e.g., functional seizures, Benbadis et al., 2020), and to ensure a representative study sample.

One strength of this review is that it includes studies from countries around the world. This geographically diverse data will provide more generalizable results on self-esteem for people with epilepsy from various countries, cultures, and ethnicities. Additionally, this review includes a considerable number of studies from non-Western countries (such as South Korea, Japan, Iran, Nigeria, and Brazil), which helps to protect against "Western bias". Furthermore, most studies had sufficiently large samples to reliably detect

associations between self-esteem and other factors.

Clinical and Social Implications

The findings of this review emphasise that self-esteem, referring to one's sense of self-worth, plays an important role in the psychosocial wellbeing of people with epilepsy and calls for individual and societal interventions. Whilst this review only included one study with people with FS, the recommendations offered below for people with ES may also be relevant for people with FS, especially as their levels of self-esteem may be even lower than those of individuals with ES (Dimaro, 2015).

Since a person's self-esteem depends not only on factors within the individual but also on how others treat them, it is pertinent to address the negative association between perceived stigma and self-esteem in people with epilepsy. The findings of this review raise the question of how we create a society where people with seizures experience and perceive less stigma and feel respected, valued, and integrated into society, which in turn could provide them with the provisions for healthy self-esteem. Reducing enacted stigma and community integration requires systemic, complex and culture-sensitive interventions, which are important for policymakers to consider but are beyond the scope of this review to discuss.

At the level of the individual patient with seizures, clinicians may consider routinely assessing and providing psychotherapeutic interventions that support healthy levels of self-esteem. Those with low self-esteem might be vulnerable to various negative psychosocial outcomes and should have access to psychotherapeutic interventions. Meta-analysis suggests that Cognitive Behavioral Therapies (CBT) can effectively increase self-esteem (Niveau et al., 2021). However, it has been debated that the pursuit of self-esteem can be problematic, as the interventions targeting increasing self-esteem rely on positively comparing the self to others, which is not always possible or helpful (Neff, 2011). Self-

compassion, like self-esteem, involves cultivating a positive and kind relationship towards oneself. However, in contrast to self-esteem, self-compassion does not require social comparisons or self-evaluations; rather, it cultivates a sense of common humanity often shared through difficult experiences and suffering (Neff, 2003). Compassion-focused therapy (CFT) interventions have been found to improve anxiety and depression (Leavis & Uttley, 2015), which are negative correlates of self-esteem in people with epilepsy. Furthermore, a cross-sectional study found that self-compassion was positively associated with adjustment and negatively associated with anxiety and depression in people with functional and epileptic seizures (Clegg et al., 2019). Therefore, clinicians might consider trialling CFT, where CBT might not be appropriate or desired by the person with seizures.

Recommendation for Future Research

Future research should continue to examine the associations of self-esteem in people with epileptic and functional seizures. There is a need for studies with more methodologically robust study designs, such as longitudinal studies or studies measuring latent variables, to establish how self-esteem contributes to and/or is influenced by various psychosocial outcomes. Furthermore, future studies should consider other methodological improvements, such as using randomised or consecutive sampling, using vEEG to diagnose people with epilepsy, reporting non-responder rates, and adequately describing study methods and results whilst reporting effect sizes and confidence intervals. In addition, future research would benefit from a consistent approach to assessing seizure and social support variables to enhance the meaningfulness and comparability of findings. Moreover, using regression models instead of correlations could help future research establish associations between variables and reduce the risk of confounders. Finally, more research is needed on what interventions might be helpful to increase self-esteem in people with seizures, which might differ in people with functional and epileptic seizures.

Conclusion

This systematic literature review evaluated and summarised current findings on associations of self-esteem in people with functional and epileptic seizures. In line with theory and previous research, self-esteem, referring to our sense of self-worth and how we *feel* about ourselves, matters in terms of positive psychosocial and quality-of-life outcomes in people with seizures. The single study examining self-esteem in people with functional seizures found that self-esteem was negatively associated with seizure frequency. The rest of the studies with ES participants found that self-esteem was negatively correlated with anxiety and depression; and positively correlated with life satisfaction and quality of life in people with epilepsy, as well as with epilepsy knowledge, self-efficacy, and helpful coping styles. Importantly, self-esteem was consistently negatively associated with anxiety and perceived stigma in people with epilepsy, which links back to the theory of how persistent negative evaluations and responses from others can impact one's sense of self-worth.

Taken together, there is a lack of evidence regarding the factors that contribute to self-esteem in individuals with functional seizures. Further research with strong methodologies is necessary to investigate the factors associated with self-esteem in individuals with epilepsy, and particularly those with functional seizures. Additionally, research on therapeutic interventions for improving self-esteem in people with ES and FS is also needed.

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Appendices

Appendix A: Studies Excluded at Full Text Screening Stage

Author	DOI/Reference	Reason for exclusion
Arcot et al.(2018)	https://dx.doi.org/10.1016/j.yebeh.2018.01.023	No correlates of self-esteem
Arida et al. (2012)	https://dx.doi.org/10.1016/j.eplepsyres.2011.07.001	Not empirical study
Arida et al. (201)	https://dx.doi.org/10.1016/j.yebeh.2009.11.003	Not empirical study
Arida, et al. (2014)	https://dx.doi.org/10.1016/j.yebeh.2014.08.031	Not empirical study
Aydemir et al (2011)	https://dx.doi.org/10.1016/j.seizure.2011.06.017	No correlates of self-esteem
Baker (1995)	Baker, G. A. (1995). Health-related quality-of-life issues: optimizing patient outcomes. Neurology.	Full text missing
Beran et al. (1987)	Beran, R. G., Major, M., & Veldze, L. (1987). Evaluation of the first 18 months of a specific rehabilitation programme for those with epilepsy. Clinical and Experimental Neurology, 23, 165-170.	Full text missing
Bhalla et al. (2013)	https://dx.doi.org/10.1111/epi.12218	No validated SE measure
Blaszczyk & Czuczwar (2016)	Błaszczyk, B., & Czuczwar, S. J. (2016). Epilepsy coexisting with depression. Pharmacological reports, 68, 1084-1092.	Not empirical study
Biondi et al. (2013)	https://www.researchgate.net/publication/287256121_QoL_in_young_epileptics_Therapeutic-rehabilitative_prospects	Full text missing
Britten et al. (1986)	Britten, N., Morgan, K., Fenwick, P. B. C., & Britten, H. (1986). Epilepsy and handicap from birth to age 36. Developmental Medicine & Child Neurology, 28(6), 719-728.	No correlates of self-esteem
Budikayanti et al (2022)	https://dx.doi.org/10.1016/j.eplepsyres.2022.106938	No validated SE measure
Chandrasekharan et al. (2021)	https://dx.doi.org/10.1016/j.yebeh.2020.107605	No correlates of self-esteem

Collings (1990)	Collings, J. A. (1990). Psychosocial Weil-Being and Epilepsy: An Empirical Study. Epilepsia, 31(4), 418-426.	No correlates of self-esteem
Collings (1994)	https://dx.doi.org/10.1016/S1059-1311%2805%2980187-6	No validated SE measure
de Boer (2008)	https://dx.doi.org/10.1016/j.yebeh.2007.12.019	not empirical study
de Souza (2006)	https://dx.doi.org/10.1016/j.yebeh.2005.10.011	No correlates of self-esteem
Dewhurst et al. (2015)	https://dx.doi.org/10.1016/j.yebeh.2015.01.010	No correlates of self-esteem
Fletcher et al (2015)	https://dx.doi.org/10.1016/j.yebeh.2015.09.002	No correlates of self-esteem
Garofalo et al (2019)	https://dx.doi.org/10.1111/epi.16352	No validated SE measure
Giovagnoli et al. (1997)	Giovagnoli, A. R., Mascheroni, S., & Avanzini, G. (1997). Self-reporting of everyday memory in patients with epilepsy: relation to neuropsychological, clinical, pathological and treatment factors. Epilepsy Research, 28(2), 119-128.	No correlates of self-esteem
Giovagnoli et al (2021)	https://dx.doi.org/10.1007/s10072-020-04742-6	Not empirical study
Hassan et al. (2017)	https://dx.doi.org/10.1097/01.XME.0000475261.72734.03	No correlates of self-esteem
Henning et al. (2021)	https://dx.doi.org/10.1111/ane.13449	No correlates of self-esteem
Hessen et al. (2008)	https://dx.doi.org/10.1016/j.seizure.2007.12.002	Not relevant participant group (only seizure free participants)
Jacoby (1994)	https://dx.doi.org/10.1016/0277-9536%2894%2990396-4	No correlates of self-esteem
Jacoby et al. (2011)	https://dx.doi.org/10.1111/j.1528-1167.2010.02973.x	No correlates of self-esteem

Kellett et al. (1997)	Kellett, M. W., Smith, D. F., Baker, G. A., & Chadwick, D. W. (1997). Quality of life after epilepsy surgery. Journal of Neurology, Neurosurgery & Psychiatry, 63(1), 52-58.	Unmet age criteria
Kuramochi et al. (2020)	https://dx.doi.org/10.1016/j.yebeh.2020.107545	No correlates of self-esteem
Lee (2005)	Lee, S. A. (2005). What we confront with employment of people with epilepsy in Korea. Epilepsia, 46, 57-58.	No correlates of self-esteem
Lee (2021)	https://dx.doi.org/10.1016/j.yebeh.2021.108186	Possible dataset overlap
McAuley et al (2001)	McAuley, J. W., Long, L., Heise, J., Kirby, T., Buckworth, J., Pitt, C., ... & Reeves, A. L. (2001). A prospective evaluation of the effects of a 12-week outpatient exercise program on clinical and behavioral outcomes in patients with epilepsy. Epilepsy & Behavior, 2(6), 592-600.	No correlates of self-esteem
Moore et al. (1994)	Moore, P. M., Baker, G. A., McDade, G., Chadwick, D., & Brown, S. (1994). Epilepsy, pseudoseizures and perceived family characteristics: a controlled study. Epilepsy research, 18(1), 75-83.	No correlates of self-esteem
Nakken (1993)	Nakken, K. O. (1993). Epilepsy and physical activity. Tidsskrift for den Norske Laegeforening: Tidsskrift for Praktisk Medicin, ny Raekke, 113(7), 848-850.	not empirical study
Neze et. Al (2009)	Neze, H., Havle, N., İlnem, M. C., & Yener, F. (2009). Epilepsi Tanısı İle Takip Edilen Kişilerde Psikiyatrik Hastalıklar ve Bunun Yaşam Kalitesi Üzerine Etkisi. In Yeni Symposium (Vol. 47, No. 3).	Full text missing
Oderinde, & Ogunniyi,(2020)	Oderinde, I. T., & Ogunniyi, A. O. (2020). The Stigma of Epilepsy Among Nigerian Subjects: A Cross-Sectional Study. African Journal of Biomedical Research, 23(SE1), 1-7.	No correlates of self-esteem
Piazzini et al (2001)	https://dx.doi.org/10.1046/j.1528-1157.2001.00510.x	No correlates of self-esteem
Persinger (1995)	Persinger, M. A. (1995). Complex partial epileptic-like signs contribute differential sources of variance to low self-esteem and imaginings. Perceptual and Motor Skills, 80(2), 427-431.	Not relevant participant group
Rabiei et al. (2022)	https://dx.doi.org/10.1016/j.seizure.2022.09.023	No correlates of self-esteem
Ragialo et al (2014)	Raglio, A., Farina, E., & Giovagnoli, A. R. (2014). Can music therapy alleviate psychological, cognitive, and behavioral impairment in epilepsy?. Epilepsy & Behavior, 31, 7-8.	No correlates of self-esteem
Reid et al. (2004)	Reid, K., Herbert, A., & Baker, G. A. (2004). Epilepsy surgery: patient-perceived long-term costs and benefits. Epilepsy & Behavior, 5(1), 81-87.	Unmet age criteria
Reiter et al. (2015)	https://dx.doi.org/10.1371/journal.pone.0144159	No correlates of self-esteem
Ryvlin (2005)	Ryvlin, P. (2005). The modern challenges of drug resistant epilepsy. Epileptic Disorders, 7(1), 1-2.	not empirical study

Salgado & Souza (2002)	Salgado, P. C. B., & Souza, E. A. P. D. (2002). Impact of epilepsy at work: evaluation of quality of life. Arquivos de Neuro-Psiquiatria, 60, 442-445.	Article not in English
Sare et al. (2007)	Sare, G., Rawnsley, M., Stoneman, A., & Duncan, S. (2007). Men with epilepsy—the lost tribe?: results of a nationwide survey of men with epilepsy living in the UK. Seizure, 16(5), 384-396.	No correlates of self-esteem
Sawangchareon et al. (2013)	https://dx.doi.org/10.5681/jcs.2013.039	No correlates of self-esteem
Smallwood et al. (2020)	Smallwood, E., Legari, S., & Sheldon, S. (2020). Group art therapy for the psychosocial dimension of epilepsy: A perspective and a preliminary mixed-methods study. Canadian Journal of Counselling and Psychotherapy, 54(3), 286-323.	No correlates of self-esteem
Smith et al. (1993)	Smith, D., Baker, G., Davies, G., Dewey, M., & Chadwick, D. W. (1993). Outcomes of add-on treatment with lamotrigine in partial epilepsy. Epilepsia, 34(2), 312-322.	Unmet age criteria
Smith et al. (1991)	Smith, D. F., Baker, G. A., Dewey, M., Jacoby, A., & Chadwick, D. W. (1991). Seizure frequency, patient-perceived seizure severity and the psychosocial consequences of intractable epilepsy. Epilepsy Research, 9(3), 231-241.	Unmet age criteria
Sullivan et al. (2013)	https://dx.doi.org/10.4276/030802213X13782044946265	No correlates of self-esteem
Taveira et al (1990)	Taveira, M. C., SIlva, A., Matos, P. M., Borges, M. I. P., Canijo, M., & Mendonça, D. (1990). Self-concept's dimensions in persons with epilepsy: implications for psychosocial development.	No correlates of self-esteem
Tedman et al (1995)	https://dx.doi.org/10.1016/S1059-1311%2805%2980065-2	No validated SE measure
Titze et al (2001)	https://dx.doi.org/10.1007/s001150170077	Full article not English
van Veen et al. (2007)	van Veen, W. H., Bos, A. E., & Lodewijkx, H. (2007). Perceived stigma and psychological well-being among people with epilepsy: A buffer effect of social support?. Psychologie & Gezondheid, 35(5), 265-269.	Full text missing
Westbrook (1991)	Westbrook, L. E. (1991). A biopsychosocial model of psychological distress in epilepsy.	Full text missing
Wo et al. (2016)	https://dx.doi.org/10.1016/j.eplepsyres.2016.10.003	No correlates of self-esteem

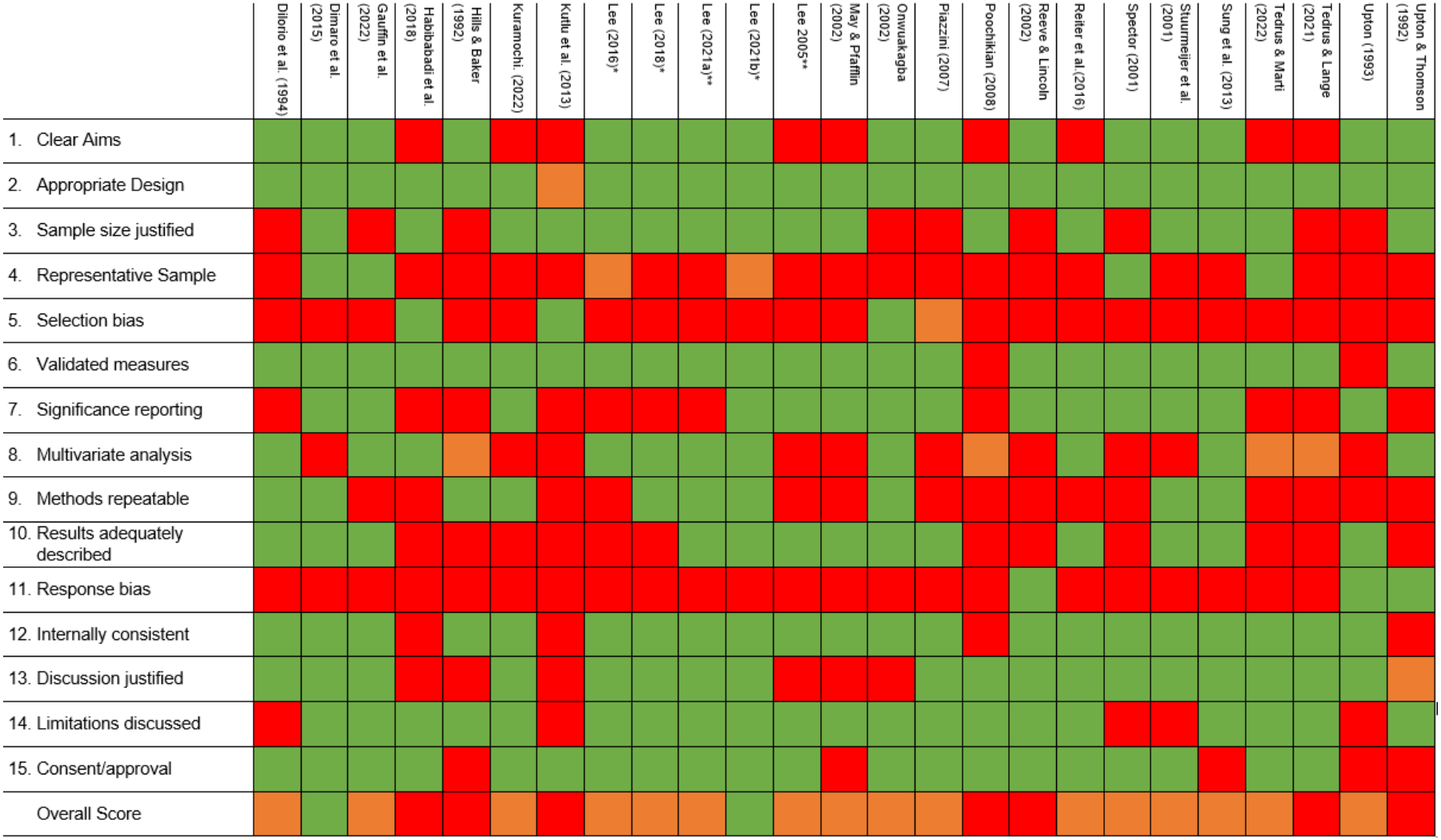
Note. SE = Self-esteem

Appendix B: Quality Assessment Tool

Introduction		Yes	No	Don't know
1.	**Were the aims/objectives of the study clear?** Yes, if there is a clear aim/hypothesis that names predictor and outcome variables OR if the study is exploratory, does it state which factors it will explore. No, otherwise.			
Methods		Yes	No	Don't know
2.	**Was the study design appropriate for the stated aim(s)?**			
3.	**Was the sample size justified?** (Index of power) Yes, if statement of a formal sample size calculation or a target sample size of 115 or more to detect a relatively small association, that is, correlation coefficient of 0.3, at 5% alpha and 90% power)) No, if sample less than 115 or if less than stated in formal sample size calculation.			
4.	**Were participant's diagnoses confirmed by EEG?** (Index of relevant target population) 'Yes' if EEG reported. 'No' otherwise.			
5.	**Was there consecutive or random selection of participants?** (An index of sample and response bias) Yes, if paper stated consecutive or random selection No, otherwise			
6.	**Were the outcome variables measured correctly using instruments/measurements that had been trialled, piloted or published previously?** (index of valid measurements) Yes, if measure compared against self-esteem is validated. No, otherwise.			
7.	**Is it clear what was used to determine statistical significance and/or precision estimates?** Yes, Standardised slope estimates/correlation coefficients, p-values, and confidence intervals are reported where appropriate No, if otherwise.			
8.	**Did the study use multivariate analysis to establish an association?** (an index of level of confounding risk/variables). Yes, if regression/Bayesian statistics/t-tests were reported No, if otherwise.			
9.	**Were the methods (including statistical methods) sufficiently described to enable them to be repeated?** Yes, if repeatable. This includes sufficient detail regarding how the questionnaires/measures were administered and by whom, and such details of the statistical analyses that can be repeated. No, if otherwise.			
Results		Yes	No	Don't know
10.	**Were the results adequately described?** Yes, if the results link back to methods and report both significant and non-significant findings relevant for the research question and self-esteem both in the tables and text. No, if otherwise.			

11.	**Did the study address response bias?** Yes, if authors reported response rates/attrition and describe nonrespondents No, if otherwise.			
12.	**Were the results internally consistent?** Yes, if authors reported results consistently across the papers No, if otherwise.			
Discussion		Yes	No	Don't know
13.	**Were the authors' discussions and conclusions justified by the results?** Yes, if authors discussed both relevant significant and non-significant results; link results back to the research question, and did not make overstatements No, if otherwise			
14.	**Were the limitations discussed?** Yes, if limitations are stated. No, if otherwise.			
Ethics		Yes	No	Don't know
15.	**Was ethical approval or consent from participants obtained?** Yes, if stated in the text. No, if otherwise.			

Appendix C: Quality Assessment Table



Note. Green = Criteria met/High quality; Red = Criteria not met/Low quality; Orange = Don't know/Moderate quality;

Section Two: Empirical Study

Examining the Role of Shame in Functional and Epileptic Seizures

Abstract

This cross-sectional study aimed to compare levels of shame and psychopathology in people with functional (FS) and epileptic (ES) seizures. The study also examined whether shame predicted psychopathology and seizure severity and frequency in people with FS and ES, and whether this association was stronger in the FS group. Participants (N = 138), who were recruited through a neurology clinic and charities, completed an online survey. Measures included self-report questionnaires exploring shame aversion, shame proneness, anxiety, depression, somatic symptoms, seizure frequency and severity. Data analyses involved t-tests, correlations, and moderated regression analyses. Results showed that people with FS had higher levels of depression and somatic symptoms than those with ES, but both groups showed elevated symptom levels. There were no differences in shame proneness, shame aversion, and anxiety between groups. Shame aversion predicted anxiety and depression in both groups but did not predict somatic symptoms and seizure variables after controlling for perceived socioeconomic status (PSES), age, and gender. Shame proneness was not a significant predictor of any self-report questionnaire score after controlling for PSES, age, and gender. The association between shame variables and psychopathology/seizures was not stronger in the FS group than in the ES group. Perceived socioeconomic status, a demographic control variable in our study, significantly predicted depression, anxiety, somatic symptoms, and seizure frequency in both groups. These findings suggest recognising the need for psychological and social interventions that can help reduce the impact of shame and percieved or actual deprivation on mental health outcomes in people with seizures.

Practitioner Points:

- Psychopathology is greater in people with FS than in those with ES. However, both people with FS and ES experience elevated levels of mental health difficulties.

- There are no differences between shame aversion and shame proneness levels in people with FS and ES, but latent factors could have influenced these findings
- Shame aversion (but not shame proneness) predicted anxiety and depression in both groups after controlling for perceived socioeconomic status, age, and gender.
- Perceived socioeconomic status was a significant predictor of psychopathologies and seizure frequency.
- There is a need for routine screening, assessment, and interventions for mental health difficulties in people with FS and ES whilst acknowledging the impact of shame and actual or percieved deprivation on their mental health outcomes.
- **Keywords:** shame, seizures, anxiety, depression, somatic symptoms

Shame is perhaps one of the most distressing emotions, and it is associated with cognitions of the self as flawed and worthless (Tracy & Robins, 2004). It is accompanied by behavioural urges to hide, withdraw, and disappear (Tracy & Robins, 2004). Shame is a social emotion that relates to our social sense of self and develops through our experiences with others, starting with early attachment figures (Jacoby, 2016). Through attuned and nurturing early caregivers, one has the basic provision to develop healthy self-esteem, helpful emotional regulation, and adaptive coping styles (Jacoby, 2016). However, adverse early life experiences and early caregivers who lack emotional attunement make one more vulnerable to developing a predisposition for maladaptive shame and low self-esteem (Jacoby, 2016; Gilbert et al., 1996). Furthermore, if shame is triggered too easily, frequently or intensely, it can increase associated maladaptive behavioural tendencies, which in turn can lead to impaired psychological functioning (Reuber et al., 2022).

Previous research examining shame in other clinical and nonclinical populations has mostly focused on *shame proneness*, defined as the tendency to experience shame readily and intensely across different situations (Tangney et al., 1992). Shame proneness has been found to be associated with anxiety disorders (Cândea & Szentagotai-Tătar, 2018), depression (Porter et al.; 2019), borderline personality disorder (Rusch et al., 2007) and somatic complaints (Fritch, 2018). More recent studies have also examined *shame aversion*; that is, the appraisal of shame as especially painful and intolerable (Schoenleber & Berenbaum, 2010). It has been proposed that shame aversion may predict stronger motivation to engage in maladaptive shame regulation behaviours than shame proneness (Schoenleber & Berenbaum, 2010). In support of this, previous research found that shame aversion contributes to psychopathology (such as borderline personality disorder, generalised anxiety disorders and post-traumatic stress disorder) beyond shame proneness (Schoenleber & Berenbaum, 2012; Schoenleber et al., 2014; Schoenleber et al. 2021).

It has recently been argued that shame may also be a crucial factor in the development of functional seizures (Myers et al., 2022; Reuber et al., 2022). Functional seizures are also commonly called psychogenic non-epileptic seizures (PNES) or dissociative seizures. Functional seizures are characterised by reductions of consciousness and self-control that involve a range of involuntary motor, sensory and mental manifestations causing disruption to normal functioning (Brown & Reuber, 2016b). Functional seizures superficially resemble epileptic seizures, but unlike epileptic seizures, functional seizures are not associated with ictal electrical discharges in the brain. Instead, functional seizures fall into the category of functional neurological disorder (American Psychiatric Association, 2013).

Since the symptoms of functional and epileptic seizures are similar, much previous research compared these two disorders. These studies have found that people with functional seizures report more traumatic experiences, have experienced greater levels of childhood abuse and neglect, are more likely to have fearful attachment styles and report more somatic complaints and dissociative experiences, than people with epilepsy and healthy controls (Brown & Reuber et al., 2016a; Gerhart et al., 2021; Holman et al., 2008). These findings contributed to the common perception that functional seizures relate to psychological difficulties (Brown & Reuber, 2016a).

However, the underlying mechanisms of functional seizures are complex and contentious. Brown and Reuber (2016b) developed the Integrative Cognitive Model (ICM) of PNES, which posits that functional seizures are automatised behavioural responses to physiological and mental arousal. They describe that the key vulnerability to functional seizures include behaviour-inhibitory dysfunction that arises from chronic stress, whilst the triggering factors include emotions associated with physiological arousal (Brown & Reuber, 2016b). Since people with functional seizures have often experienced traumatic experiences (Holman et al., 2008) and subsequent stigma related to their condition (Rawlings et al.,

2017), this may lead to them experiencing increased levels of shame. The fact that shame is a particularly intolerable emotion suggests that it may increase arousal and reduce the effectiveness of behavioural inhibition, and it may also trigger functional seizures directly (Reuber et al., 2022).

Social emotions like shame may also play a role in epileptic seizure disorders, although shame would not be considered a likely direct aetiological contributor to epileptic seizures. However, like patients with functional seizures, those with epilepsy are characterised by high levels of stigma (Mayor et al., 2022a). They have also been found to manifest high levels of self-disgust (Mayor et al., 2022b), an emotion not studied in patients with functional seizures so far. Previous research also suggests elevated levels of mental health difficulties in people with epilepsy (Lu et al., 2021).

In addition, it's important to take into account demographic and social factors that can affect levels of shame when conducting research on the topic. Studies have shown that lower socio-economic status has been associated with feelings of "internalised inferiority" and shame (Bosma et al., 2015). This is not suprising, as shame is an emotion that is triggered by threats to one's social self or status (Gilbert, 2011). Furthermore, prolonged experiences of shame have been linked to increased activity of pro-inflammatory cytokines and cortisol levels (Dickerson et al., 2004). Relating to this, research also suggests that perceived deprivation, or a sense of lower socio-economic status, can lead to negative health outcomes (Demakakos et al., 2008) and increased mortality rates, even after controlling for actual income (Yngwe et al., 2012). On a different note, previous studies have consistently shown that shame proneness is higher in females (Orth et al., 2010; Tangney & Dearing, 2002), while older individuals tend to have lower levels of maladaptive shame (Orth et al., 2010).

The observations on the significant impact of shame on health and mental health provide a rationale for studying shame in both epileptic and functional seizure disorders and for exploring whether it contributes to current (adulthood) psychopathology.

Hypotheses:

(1) We expected that people with functional seizures would have greater levels of shame proneness, shame aversion, somatic symptoms, anxiety and depression than people with epileptic seizures.

(2) We predicted that shame aversion and shame proneness would predict anxiety, depression, somatic symptoms, seizure severity and seizure frequency in both groups, but this association will be stronger in the functional seizure group.

Methods

Design

This was a cross-sectional, comparative and correlational study, with two natural groups including people with epileptic seizures (ES) and functional seizures (FS). The study involved an online survey and convenience sampling.

Participants

Participants were recruited from outpatient neurology clinics at a South Yorkshire hospital in the United Kingdom. Consultant Neurologists informed patients about the study. If patients were interested, with their consent, the main researcher emailed them a link to the online study website. To optimise recruitment, membership-led organisations for individuals experiencing epileptic or functional seizures (see acknowledgements) also advertised the study on their online platforms. Recruitment took place between December 2022 and March 2023.

Participants were included if they were a) 18 years old; b) could read and write in English c) could complete the online questionnaire on their own, without help; d) had a self-declared diagnosis of functional or epileptic seizures as confirmed by a physician (e.g. neurologist or psychiatrist). Participants were excluded if a) were younger than 18 years old; b) could not confirm their diagnosis; c) had both epileptic and functional seizures.

Statistical Power

A priori power analysis was conducted using the 'G*Power 3' software to attain the minimum sample size required to find an effect. Focusing on the study's primary aim, the power analysis was based on a linear multiple regression analysis. The effect size estimate considered the results of a study by Thapar et al. (2008), which investigated the relationship between psychological factors and subsequent seizures. Thapar et al. (2008) identified a model in which baseline measures of stress, anxiety and depression explained 12% (R^2 = 0.12) of subsequent seizure recency. According to Cohen (1998)**,** $0.02 <= R^2 < 0.13$ indicates a small effect size. Thus, the $R^2 = 0.12$ found by Thapar et al. (2008) would be categorised as a small effect.

Based on this, we assumed an effect size of f2 = 0.10, a significance level of $\alpha = .05$, and 80% power. The numerator df was 5, as five number of predictors (including shame aversion, shame proneness, and covariates of age, gender, and socioeconomic status) were included. This resulted in a denominator df of 128, suggesting a total sample size of 134 participants.

Ethical Approval

Ethical and Health Research Authority approval (Reference number: 22/YH/0213, Appendix A) was obtained for the study. Participation was voluntary, and participants consented before taking part.

Procedure

The survey ran on Qualtrics (https://www.qualtrics.com), an online data collection platform. To access the online survey platform, participants had to follow the link provided by the researcher or as advertised by membership-led seizure-specific organisations (See Appendix B for the online Study Advertisement Poster). When clicking the link, participants were presented with an information sheet (Appendix C) and a consent form (Appendix D). Next, participants who consented to participate were required to complete a series of brief screening questions (Appendix E) to confirm their diagnosis of functional seizures or epileptic seizures, in order to determine whether they were eligible to complete the study. After that, eligible participants completed the measures, starting with demographics and continuing with shame proneness, shame aversion, seizure severity, somatic symptoms, depression and anxiety. At the end of the study, participants had the option to participate in a guided 5-senses grounding exercise (Appendix F) and were presented with a debriefing sheet (Appendix G).

Measures

All measures can be found in Appendix H. In addition to the questionnaire data described below, demographic data were collected (including age, gender, ethnicity, educational and employment status, and perceived socioeconomic status).

Perceived socioeconomic status (PSES)

PSES was measured as a visual scale where participants were asked to indicate where they think they stand on the socioeconomic ladder (Adler et al., 2000). The instructions were as follows: “At the top of the ladder are the people who are the best off, those who have the most money, most education, and best jobs. At the bottom are the people who are the worst off, those who have the least money, least education, worst jobs, or no job. Please place an ‘X’ on the rung that best represents where you think you stand on the ladder.”

Shame Proneness

The short version of the Test of Self-Conscious Affect Scale (TOSCAS-3; Tangney et al., 2000) was used to measure internalised and global shame. The short version of TOSCA-3 includes 11 negative scenarios that yield six subscales of guilt-proneness, shame-proneness, detachment, and externalisation. Items are scored on a 5-point Likert-type scale, ranging from one (not likely) to five (highly likely). Scores range from 11 to 55; higher scores represent higher shame proneness. The Cronbach's alpha for the TOSCA-3 was acceptable (α =.76).

Shame Aversion

The Shame-Aversive Reactions Questionnaire (ShARQ, Schoenleber & Berenbaum, 2010) assessed intolerance and aversion to shame. The ShARQ includes 14 items, half of which are reverse scored. Higher scores on the ShARQ indicated higher levels of shame aversion. Answers to the ShARQ are provided using a 7-point Likert-type scale. Cronbach's alpha was α = .89 for the ShARQ, indicating good internal consistency.

Seizure Severity

The Liverpool Seizure Severity Scale (LSSS-2, Scott-Lennox et al. 2001) was used to measure recent seizure severity. The measure includes a screening question ensuring that only patients with recent seizure experience could proceed to complete the questionnaire. Those participants who did not have seizures in the last 4 weeks could not complete the rest of the questionnaire. Each of the 12 items on the LSSS-2 is scored on a Likert scale, with higher scores indicating greater seizure severity. To create the final score, the sum of the responses to questions 1–12 is divided by 40, and the dividend is multiplied by 100. This linear transformation of the sum of the responses produces a 'most severe' score that ranges from 0 (no seizures) to 100 (very severe seizure). The test-retest reliabilities ranged from 0.74 – 0.80 for the LSSS-2.

Seizure Frequency

The Seizure Frequency Scale (developed by thesis supervisor Professor Markus Reuber) requires participants to choose between five options that best describe the frequency of their seizures over the last year. The options are: 1) I usually have more than one seizure per day; 2) I usually have more than one seizure per week but fewer than one seizure per day; 3) I usually have more than one seizure per month but fewer than one seizure per week; 4) I usually have more than one seizure per year but fewer than one seizure per month; 5) I have not had any seizures in the last year.

Depression

The 8-item version of the Patient Health Questionnaire (PHQ-8; Kroenke et al., 2001) was used to assess depression severity. Each of the 8 items can be scored from 0 (not at all) to 3 (nearly every day); higher scores indicate higher levels of depression. The PHQ-8 can be used as a depression measure for population-based studies, where a score of 10 or greater can define current depression (Kroenke, 2009). Internal reliability of the item PHQ-8 was excellent (Cronbach's α of $\alpha = 0.90$).

Anxiety

The 7-item Generalized Anxiety Disorder scale (GAD-7; Spitzer et al., 2006) assesses overall severity of anxiety. Each item is scored on a four-point Likert scale (0–3), with total scores ranging from 0 to 21, with higher scores reflecting greater anxiety severity. A GAD-7 score of 10 or greater is suggested to identify cases of a Generalised Anxiety Disorder (Spitzer et al., 2006). Internal consistency of the GAD-7 was excellent (Cronbach $\alpha = .92$).

Somatic Symptoms

The 8-item Somatic Symptom Scale-8 (SSS-8; Gierk et al., 2014) assesses somatic symptom burden. The SSS-8 has a 5-point Likert-type scale ranging from 0 (not at all) to 4

(very much). The total score ranges from 0 to 32, with higher scores indicating a greater somatic symptom burden. Cut-off points are suggested as no to minimal (0-3 points), low (4-7 points), medium (8-11 points), high (12-15 points), and very high (16-32 points) somatic symptom burden. The SSS-8 had good reliability (Cronbach $\alpha = 0.81$).

Data Analyses

For the statistical analyses, IBM SPSS Statistics for Windows (Version 28; 2021) was utilised. Sample characteristics, demographics, and condition-specific variables are described in Table 1. A preliminary analysis was carried out to test differences between groups on demographic and condition-specific variables using t-tests (for continuous parametric variables), Mann-Whitney U tests (for continuous non-parametric variables), or Chi-Square test (for categorical variables), see Table 1. Additionally, a preliminary Pearson's and Spearman's correlation analysis was performed to test the strength of association between variables (Table 2).

Hypothesis 1. was tested using five Student's t-tests analyses (Table 2) to compare groups on the shame aversion, shame proneness, depression, anxiety, and somatic symptoms variables. Assumptions of the t-test were tested using histograms (for normal distribution), QQ plots (for normality of variance), and Lavine's test (for equality of variances). The variables shame proneness and shame aversion showed a negatively skewed distribution. Therefore, both variables were transformed by reflecting and raising them to the square root. After that, all assumptions for the t-tests were met. To correct for family-wise error rate, the Holm-Bonferroni method[12] was used to adjust alpha levels ($\alpha_1 = .01$, $\alpha_2 = .013$, $\alpha_3 = .017$, $\alpha_4 = .017$, $\alpha_5 = .017$) for the group comparisons (Holm, 1979, using Excel file developed by Gaetano, 2013).

Hypothesis 2. was tested with five multiple hierarchical regressions that were carried out for each dependent variable (depression, anxiety, somatic symptoms, seizure frequency, seizure severity). A preliminary correlation analysis, including all variables, was conducted (see Table 3). The assumptions of linear regression were tested using PP-plots (for normal distribution of residuals), scatter plots (for homoscedasticity of residuals), partial regression plots (for linearity between predictor and dependent variables) and checking the Variance Inflation Factor of predictor variables in each regression analyses (for multicollinearity). All assumptions for the hierarchical regression analyses were met.

The hierarchical regression analyeses are described in *Table 4* and *5*. For each five hierarchical regression analyses, in Step 1, socioeconomic status, age, and gender were added as covariates. In Step 2, the variables shame aversion, shame proneness, and 'group membership' were added (the latter being a dummy coded variable involving epilepsy d=0 or functional d=1 seizure groups). Finally, two moderators were entered in Step 3. The moderator variables were created from the product of the standardised independent variables (shame aversion, shame proneness) and the standardised dichotomous dummy coded group variable (epilepsy vs functional seizure group). To reduce multicollinearity when testing the moderating effect, all moderator variables and independent variables were standardised (except dummy variables) following guidance of Aiken and West (1991, p.31). To correct for family-wise error rate, the Holm-Bonferroni method was used to adjust alpha levels (α_1 = .01, α_2 = .013, α_3 = .017, α_4 = .025, α_5 = 0.05) for the model statistics of the moderation analyses (Holm, 1979; using Excel file developed by Gaetano, 2013).

Results

Table 1 describes participant characteristics. One hundred ninety-two participants started the study survey. Three participants discontinued after the consent form, but before completing the diagnostic questionnaire. One participant was excluded due to not having a diagnosis of functional or epileptic seizures. Two were excluded as their diagnosis was not confirmed by a physician. Sixteen were excluded due to having a mixed diagnosis of functional and epileptic seizures. Finally, one participant was excluded due to indicating invalid responses. Twenty-nine participants started but did not complete all questionnaires; therefore, they were excluded.

Demographic and Condition-Specific Variables

In total, 138 participants were included in the study (age 18 and 67 years, $M = 38.7$, $SD = 12.2$). Most participants were female ($n = 114$; 82.6%). There was a higher proportion of female participants in the FS than in the ES group ($p < .05$), and one participant identified as non-binary. In the ES group, most participants were British (92.9%), whereas the FS group was about half British (54.4%) and half international (45.6%), indicating a significant difference in country of residence ($p < .001$). The international participants in the functional group came from the USA (16%), Australia (12%), Canada (8%), New Zealand (4%), and European high-income countries (4.4%). In the epilepsy group, international participants came mostly from English-speaking countries (5.6%), and one participant (1.4%) came from a European high-income country. There were no differences between groups in terms of ethnicity and education. Most participants indicated white ethnicity (89.9%). All participants had at least secondary education, and about half had a university degree. There were significant differences between the groups in terms of employment ($p < .001$). In the ES group, 71.4% indicated being employed or studying full-time, and 12.9% indicated being on sickness/disability leave, whereas this was 30% and 57.3% in the FS group, respectively.

This could have been reflected in how the FS group perceived their socioeconomic status as significantly lower than the ES group ($p < .001$).

In terms of seizure severity, the ES group indicated a median score of two, meaning that most participants had usually more than one seizure per year, but fewer than one seizure per month. The FS group reported a median of four, meaning that most of the participants had more than one seizure per week but fewer than one seizure per day. This indicated that the FS group had significantly more frequent seizures than the ES group ($p < .001$). In the last four weeks, 69% of participants in the FS group reported having had at least one seizure, in contrast to 51% in the ES group. Results showed that people in the ES group reported significantly stronger seizures, than in the FS group($p < .001$).

Table 2 shows the group means of people with ES and FS on the shame and psychopathology questionnaire scores. The FS group met the diagnostic cut-off level for anxiety and depression, and the ES group met the diagnostic cut-off for depression. People with ES reported high, and the FS group very high levels of somatic symptoms.

Table 1

Demographic and Condition Variables

	Epilepsy (N = 70)	Functional (N = 68)	Statistics	95% Significance (two-tailed)
Demographic variables				
Age	M = 38.1 (SD = 11.6)	M = 39.3 (SD = 12.9)	Mann-Whitney	p = .49
Gender	77% Female	88% Female 1 non-binary	Chi-Square	p = .52
Ethnicity			Chi Square	p = .93
White	64	60		
Asian	1	2		
Black	1	1		
Mixed	4	3		
Latina	0	1		
Native American	0	1		
Country			Chi Square	p < .001
British	92.9%	54.4%		
International	7.1%	45.6%		
Perceived Socioeconomic Status	M = 5.23 (SD = 1.9)	M = 3.94 (SD = 2)	t-test	p < .001
Employment			Chi Square	p < .001
Paid work/full-time study	71.4%	30.8%		
Sickness/Disability leave	12.9%	57.3%		
Other	15.7%	11.9%		
Education			Chi Square	p = .43
Secondary/vocational	21.4%	27.9%		
Post-secondary certificate	22.9%	13.2%		
University degree	50%	54.4%		
Other	5.7%	4.5%		
Condition variables				
Seizure severity	M = 61.94 (SD = 18.03)	M = 50.89 (SD = 16.21)	t-test	p = .03
Seizure frequency	M = 2.47 (SD = 1.22) Median = 2	M = 3.75 (SD = 1.75) Median = 4	t-test	p < .001

T-tests

Table 2 summarises the results of the group means, and standard deviations results of t-test analyses. In accordance with Hypothesis 1, the FS group had significantly higher depression (t (136) = -3.61; $p < .001$) and somatic symptoms scores compared to the ES group (t (136) = -5.31; $p < .001$) (Table 3). However, in contrast with this hypothesis, the t-tests showed no differences between groups in anxiety (t (136) = -1.29; p =.1), shame proneness (t (136) = .35; p = .36) and shame aversion (t (136) = -.14; p = .45).

Table 3
Group Differences Between Dependent Variables

	Epilepsy (N = 70)	Functional (N = 68)	Test values	95% Significance level (one-tailed)
Depression	*M* = 12.34 *SD* = 6.77	*M*=16.51 *SD*=6.77	*t* (136) = -3.61	*p* < .001 *d* = -.62
Anxiety	*M* = 9.21 *SD* = 5.86	*M*=10.54 *SD*=6.24	*t* (136) = -1.29	*p* = 0.1 *d* = -.22
Somatic symptoms	*M* = 13.41 *SD* = 6.71	*M* = 19.29 *SD* = 6.29	*t* (136) = -5.31	*p* < .001 *d* = -.55
Shame proneness	*M* = 38.48 *SD* = 9.39	*M* = 39.40 *SD* = 7.70	*t* (136) = .35	*p* =.36 *d* = .06
Shame aversion	*M* = 66.17 *SD* = 13.25	*M* = 65.31 *SD* = 15.13	*t* (136) = -.14	*p* = .45 *d* = -.02

Correlations Between Predictor and Dependent Variables

Table 3. summarises the results of the correlation analyses. Amongst the demographic variables, perceived socioeconomic status (PSES) was significantly negatively associated with depression (r = -.445; p < .01), anxiety (r = -.224; p < .01), somatic symptoms (r = -.391; p < .01), shame aversion (r = -.369; p < .01) and shame proneness (r = -.417; p < .01), and seizure frequency (r = -.348; p <.01); but not with seizure severity (r = .129; p = .21). Being male was associated with higher PSES (r = -.170; p < .01). Age was significantly

negatively correlated with shame aversion (r = -.250; p <.01), and shame proneness (r = -.206; p <.05), but not correlated with the other variables. On the other hand, being female was positively associatied with shame aversion (r = . 258; p < .01) and shame proneness (r = . 382; p < .01).

Shame aversion correlated significantly positively with depression (r = .491; p < .01), anxiety (r = .527; p < .01), somatic symptoms (r = .260; p < .01), seizure severity (r = .238; p = .02), but not with seizure frequency (r = -.043). Similarly, there was a significant positive correlation between shame proneness and depression (r = .389; p < .01), anxiety (r = .396; p <.01), and somatic symptoms (r = .280; p < .01), but shame proneness did not correlate significantly with seizure frequency (r = .028) and severity (r = .109). There was a strong positive association between shame aversion and shame proneness (r = .628; p < .01).

Table 3
Correlations Among Study Variables

Variable	1	2	3	4	5	6	7	8	9	10
1. Age	-									
2. Perceived SES*	.013	-								
3. Gender	-.259**	-.170*								
4. Depression	-.093	-.445**	.125	-						
5. Anxiety	-.142	-.224**	.082	.731**	-					
6. Somatic symptoms	-.012	-.391**	.074	.607**	.493**	-				
7. Shame aversion	-.250**	-.369**	.258**	.491**	.527**	.260**	-			
8. Shame proneness	-.206*	-.417**	.382**	.389**	.396**	.280**	.628**	-		
9. Seizure frequency	.051	-.348**	-.017	.240**	.086	.296**	-.043	.028	-	
10. Seizure severity	-.174	-.129	-.134	.131	.136	.070	.238*	.109	.058	-

Note. SES = Socioeconomic status; For gender (male code =1; female code =2) Spearman's rho was calculated. Pearson's correlation was calculated for all variables.

*p< .05 **p<. 01

Regression Analyses

In terms of the control variables, PSES was a significant predictor for depression (β = -.44, p < .001), anxiety (β = -.26, p < .01), somatic symptoms (β = -.40, p < .01), and seizure frequency (β= -.37, p < .001), but not for seizure severity (β = -.15, p = .13). Age (β = -.23, p = 0.03) and being female (β=-.22, p = .04) were significant predictors for seizure severity; specifically, being younger and being female was associated with greater seizure severity.

In support of Hypothesis 2, *shame aversion* predicted significant variance in depression (β = .39, p < .01) and anxiety (β = .47, p <.001) after controlling for perceived socioeconomic status, age, and gender control variables. However, *shame aversion* did not predict significant variance in somatic symptoms (β = .15, p = .13), seizure frequency (β = -.11, p = .27), and seizure severity (β = 0.15, p = .25). *Shame proneness* did not predict significant variance over and above the variance explained by perceived socioeconomic status for depression (β = .07, p = .50), anxiety (β = .15, p = .16), somatic symptoms (β = .13, p = .23), and seizure severity (β = -.04, p = .77), and seizure frequency (β = .00, p = .97)

Furthermore, in contrast to our predictions, the moderation analyses indicated that after controlling for age, gender, socioeconomic status, and the main effects of shame variables and group membership, there was no interaction effect between ‘group and shame proneness’ and ‘group and shame aversion’ variables for any of the dependent variables. This means the strength of the relationship between shame variables and psychopathology and seizure variables was not stronger in the FS group.

Table 4

Regression Analyses of Group membership as Moderator of the Relation Between Shame Aversion and Shame Proneness and Seizure Severity and Seizure Frequency

Predictor	ΔR^2	ΔF	*Beta [95%CI]*
1. Depression as dependent variable			
Step 1	.20	F (3, 132)=11.5**	
Age			-.08 [-.14, .05]
Gender			.02 [-.37,.50]
Perceived SES			-.44 [-.59, -.28]**
Step 2	.37	F (6, 129)=12.73**	
SP			.07 [-.13, .26]
SA			.39 [.21, .58]**
Group			.24 [.19, .79]**
Step 3	.38	F (8, 127)=9.69**	
SP * group			-.12 [-.57, .20]
SA * group			.00 [-.37, .37]
2. Anxiety as dependent variable			
Step 1	.07	F (3, 132)=3.33*	
Age			-.14[.31, -.03]
Gender			-.01 [-.49, .44]
Perceived SES			-.26 [-.39, -.06]**
Step 2	.31	F (6, 129)=9.69**	
SP			.15 [-.06, .35]
SA			.47 [.28, .67]**
Group			.14 [-.03, .60]
Step 3	.31	F (8, 127)=7.20**	
SP * group			-.07 [-.48, .30]
SA * group			.02 [-.38, .44]
3. Somatic symptoms as dependent variable			
Step 1	.16	F (3, 132)= 8.240**	
Age			-.01 [-.17,.16]
Gender			.00[-.43,.45]
Perceived SES			-.40[-.55,-.23]**
Step 2	.29	F (6, 129)= 8.665**	
SP			.13[-.08, .33]
SA			.15 [-.04, .34]
Group			.36[.39,1.02]**
Step 3	.30	F (8, 127)= 6.691**	
SP * group			.11 [-.23, .60]
SA * group			-.19 [-.65, .14]

Note. SES = Socioeconomic Status; SA = Shame aversion; SP=Shame proneness. Gender is dummy coded variable, with male d = 0 and female d = 1;

*p< .05 **p<. 01

Table 5

Regression Analyses of Group Membership as Moderator of the Relation Between Shame Aversion and Shame Proneness and Seizure Severity and Seizure Frequency

Predictor	ΔR^2	ΔF	*Beta (95% CI)*
	4. Seizure Severity		
Step 1	.10	F (3, 89)= 2.97*	
Age			-.23 [-.44, -.02]*
Gender			-.22 [-1.13,-.03]*
Perceived SES			-.15 [-.37,.05]
Step 2	.20	F (6, 86)= 3.68**	
SP			-.04 [-.32,.24]
SA			.15 [-.11,.41]
Group			-.32 [-1.07,-.23]**
Step 3	.22	F (8, 84)= 2.97**	
SP * group			.22 [-.84,.21]
SA * group			.26 [-.19, .84]
	5. Seizure frequency		
Step 1	.11	F (3, 132)= 6.03**	
Age			.04 [-.13, .20]
Gender			-.08[-.67,.23]
Perceived SES			-.37[-.53, -21]**
Step 2	.28	F (6, 129)= 9.537**	
SP			.00 [-.20, .21]
SA			-.11 [-.30,.09]
Group			.41[.51; 1.14]**
Step 3	.27	F (8, 127)= 7.202**	
SP * group			.02[-.37,.45]
SA * group			.09[-.27, .51]

Note. Note. SES = Socioeconomic Status; SA = Shame aversion; SP=Shame proneness. Gender is dummy coded variable, with male d=0 and female d=1.

*p< .05 **p<. 01

Discussion

The current study examined differences between people with functional (FS) and epileptic seizures (ES) in terms of shame and psychopathology. Furthermore, it was hypothesised that shame proneness and aversion would predict psychopathology and seizures in both groups, and this association would be stronger in the functional seizure group. In support of the first hypothesis, people with FS experienced higher depression and somatic symptoms than people with epilepsy. However, in contrast to our expectations, no differences

were found between groups in terms of anxiety, shame proneness and shame aversion. In accordance with the second hypothesis, shame aversion predicted depression and anxiety after controlling for perceived socioeconomic status (PSES), age, and gender in both groups. However, shame aversion did not predict somatic symptoms, seizure frequency and severity after controlling for PSES, age, and gender. Moreover, shame proneness was not a significant predictor of any psychopathology or seizure variable after controlling for PSES, age and gender. In contrast to expectations, the strength of association between shame and psychopathology did not differ between the functional seizure group and the epilepsy group. An important ancillary finding emerged from our data: PSES was a significant predictor of depression, anxiety, somatic symptoms, seizure frequency; and was negatively associated with shame aversion, and shame proneness. Furthermore, PSES was significantly lower in the FS group than in the ES group.

Differences Between People with FS and ES

In this study, both people with epilepsy and functional seizures experienced elevated clinical levels of depression and somatic symptoms, and these levels were significantly higher in people with FS, than people with ES. Whilst only the FS group experienced clinical levels of anxiety, the differences in anxiety between participants with FS and ES did not reach significance. These findings are similar to the findings of previous research. A meta-analysis found that people with FS tended to have higher levels of anxiety and depression than people with ES; however, these differences only reached significant levels for anxiety and not for depression (Diprose et al., 2016). The higher somatic symptom scores in the FS group compared to the ES group found in this study align with previous findings (Brown & Reuber, 2016). Overall, most previous studies indicated trends of higher psychopathology levels in people with FS than people with ES; however, whether these differences reached

significance may depend on methodological differences in the studies (see Diprose et al., 2016).

There were no differences in terms of shame aversion and shame proneness between groups. This finding may reflect true similarities between groups regarding shame processes. Both people with functional and epileptic seizures experience high levels of stigma (Annandale et al., 2022; Mayor et al., 2022a) and elevated levels of psychopathology compared to non-clinical populations (Diprose et al., 2016), which are factors linked to elevated shame and could impact both conditions (Leaffer et al., 2014; Reuber et al., 2022).

Shame as a Predictor of Psychopathology

This study found that shame aversion predicted anxiety and depression in both people with FS and ES, after controlling for PSES, age, and gender. This finding contributes to previous evidence in other clinical populations (Schoenleber & Berenbaum, 2012; Schoenleber et al., 2014; Schoenleber et al., 2021), suggesting that shame aversion might be an important underlying transdiagnostic process that contributes to psychopathology. On the other hand, shame proneness was not a significant predictor for any psychopathology or seizure-related measure after controlling for socioeconomic status, age and gender. Whilst shame is a painful emotion, perhaps it is not the experience of it, but how we respond to it matters the most in terms of its contribution to psychopathology. According to mindfulness-based theories, it's natural to experience a variety of positive and negative emotions. The suffering doesn't come from the emotions themselves, but from our unhelpful reactions to them, such as aversion to negative emotions and craving for positive ones (Teasdale & Chaskalson, 2011a & 2011b). Our finding aligns with other studies that showed shame aversion was a better predictor of various psychopathologies than shame proneness (Schoenleber & Berenbaum, 2012; Schoenleber et al., 2014; Schoenleber et al., 2021).

Previous studies that looked at the relationship between shame and somatisation found a weak association between somatic symptoms and shame; however, these studies involved non-clinical samples and did not control for demographic variables (Fritch, 2018; Pines, 2006). Conversely, in the present study, neither shame aversion nor proneness were associated with somatic symptoms in the ES or FS groups. To the author's knowledge, this is the first study to examine the role of shame in clinical populations with clinical levels of somatic symptoms in both the ES and FS group, whilst also controlling for significant demographic variables. Thus, previous associations between shame and somatic symptoms may not reflect the experiences of those considered 'clinical' patients – particularly when levels of somatic symptoms are high.

Previous research suggests that approximately one-third of somatic symptoms cannot be explained medically (Kroenke et al., 2002; Prince et al., 2007), and the preoccupation with somatic symptoms can be an emotionally avoidant behaviour where somatisation functions as denial of emotional pain (Higgings & Edler, 1995). Given this previous research, the lack of association between shame and somatic symptoms, in the present study, may possibly reflect a latent relationship between variables. To elaborate on this idea, shame proneness and aversion may not have predicted somatic symptoms in either group, because those with higher somatisation (reporting higher somatic symptoms) may be less aware, or in denial, of painful cognitive and affective experiences of shame. In other words, somatisation may function as a psychological defence against shame; therefore, those high in somatisation might be less likely to endorse painful statements about the self on shame questionnaire measures.

Additionally, if somatisation functions as an avoidance of experiencing shame, this could provide an alternative hypothesis for the lack of differences found in shame levels between groups. As such, the significantly higher reporting of somatic symptoms in the FS

group could have been linked with the FS group underreporting on the shame measures. Therefore, future research would benefit from utilising implicit measures of shame (i.e. as used in Rüsch et al., 2007), or measures that include somatic responses to shameful social situations alongside the traditional shame measures.

Perceived Socioeconomic Status (PSES), an Influential Control Variable

Interestingly, there was a significant difference between groups, wherein individuals with FS had notably lower employment rates and PSES compared to those with ES, despite having similarly high levels of education. These findings suggest that those with FS may face considerable challenges when it comes to everyday functioning, which is consistent with previous research (Robson et al., 2018).

Furthermore, PSES predicted depression, anxiety, somatic symptoms, and seizure frequency. This finding is not unique to this sample, as many previous studies found that perceived and actual social deprivation (Kivimäki et al., 2020; Mishra & Carleton, 2015; Visser et al., 2021) and social inequalities (Pickett & Wilkinson, 2015) were associated with various health and mental health difficulties. Moreover, a data linkage study found evidence that increased deprivation was linked to increased rates of epilepsy (Pickerel et al., 2015). Although our study only assessed individuals' *self-perceived* socioeconomic status, the FS group's notably low employment rates suggest a potential *actual* low socioeconomic status.

The results of this study highlight how social and demographic factors can impact psychological factors, which is important to consider when studying clinical populations (Bronfenbrenner, 1992). To better understand the relationship between psychological variables and shame, future studies should take into account the significant influence of socioeconomic status on one’s perception of social standing and feelings of shame.

Furthermore, future studies should match participants in terms of (perceived) socioeconomic status, age and gender.

Implications

The study results call for the clinical recognition that people with both FS and ES experience elevated levels of mental health difficulties, and shame aversion appears to contribute to these difficulties in both groups. Shame aversion may be an underlying, transdiagnostic factor that plays a role in various psychopathologies, and future studies could benefit from further investigating the role of shame in people with seizures. Providing the high percentage of mixed diagnoses amongst people with functional and epileptic seizures (Anzellotti et al., 2020), and the high prevalence of mental health difficulties in both conditions, there is a call for a holistic assessment and treatment, where the impact of various bio-psycho-social factors are considered (Elliott & Richardson, 2014). Relating to this, neurology services would benefit from integrated models of care (Glen et al., 2019), where people with seizures could be regularly screened, assessed, and offered interventions for mental health difficulties, and offered support for their social needs.

Furthermore, it would be interesting for clinicians to trial therapies that focus on promoting helpful shame regulation through self-compassion and mindfulness/acceptance strategies, as practised in Compassion-Focused Therapies (CFT, Gilbert, 2011) and Acceptance Commitment Therapies (ACT, Lundgren et al., 2008). Preliminary evidence from a cross-sectional study shows that self-compassion was positively associated with adjustment and negatively related to anxiety and depression in both people with ES and FS (Clegg et al., 2019). Furthermore, ACT was found to contribute to positive mental health outcomes in both people with epilepsy (Dewhurst, 2015) and functional seizures (Barrett-Naylor, 2018).

The current findings also emphasize the need for a less stigmatising, more inclusive, and equitable society, given the significant impact of perceived socioeconomic status on mental health outcomes and seizure frequency observed in our results.

Limitations and Research Recommendations

One limitation of the study is its cross-sectional design. Since shame, psychopathology, and seizure variables were all measured simultaneously, the design had limited ability to establish causal relationships between these variables. Future studies with longitudinal designs would be better suited to address causation. A second limitation of the study is the uncertainty surrounding the representativeness of the sample. This is due to the use of convenience sampling and the fact that participants self-declared their diagnosis. To improve future research, it would be beneficial to recruit participants consecutively, with confirmed diagnoses through vEEG assessment. While this requires more resources, it would increase the representativeness of study samples.

It is important to acknowledge, that most of the study participants identified with having white ethnicity, and came from high-income Western countries. This limits the study's generalizability. It is uncertain whether our findings apply to people from various non-Western cultural backgrounds and from developing countries, where there are higher prevalence rates of epilepsy (Neligan & Sander, 2009). Another limitation of this study was that 17% of participants dropped out during the questionnaire completion phase, but the reasons for this are unknown. Additionally, including a non-clinical control group could provide useful baseline comparisons for measures of shame and psychopathology.

The study’s strengths included a large clinical sample, which yielded sufficient power to detect an effect. Furthermore, the data analysis involved hierarchical modelling, which allowed the assessment of the unique contribution of each study variable, after controlling for

demographics. To the author's knowledge, this was the first study to assess the role of shame in people with epileptic and functional seizures, which could provide preliminary evidence for future studies to build on.

Conclusion

The current study showed that both people with FS and ES experience elevated and clinical levels of somatic symptoms and depression, and the FS group showed clinical levels of anxiety. When comparing the two groups, the FS group had a significantly higher somatic symptom level and depression, but did not signficantly differ in terms of anxiety levels from the ES group. In both groups, shame aversion predicted anxiety and depression, but not somatic symptoms, after controlling for PSES, age and gender. Shame proneness did not predict any psychopathology or seizure variable, after controlling for PSES, age, and gender variables. Interestingly, PSES was a significant predictor of depression, anxiety, somatic symptoms, and seizure frequency.

These findings indicate a place for an integrated care model for people with FS and ES, where the medical, psychological and social needs of patients are acknowledged and addressed. To improve patient outcomes, regular screening, assessment, and intervention for mental health difficulties for people with both ES and FS would be desirable. Given the contribution of shame aversion to anxiety and depression, psychological interventions that help people to regulate shame in helpful ways may especially benefit people with seizures.

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Appendices

Appendix A: NHS Ethics Committee and Health Research Authority Approval

NHS
Health Research Authority

Yorkshire & The Humber - South Yorkshire Research Ethics Committee
NHSBT Newcastle Blood Donor Centre
Holland Drive
Newcastle upon Tyne
NE2 4NQ

Telephone: 0207 1048091

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

01 December 2022

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

Dear Professor Reuber

Study title:	**Examining the role of shame in seizure disorders**
REC reference:	**22/YH/0213**
Protocol number:	**V2**
IRAS project ID:	**319791**

Thank you for your letter of 18 November 2022, responding to the Research Ethics Committee's (REC) request for further information on the above research [and submitting revised documentation].

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

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

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

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

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

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit:
https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at:
https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

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

After ethical review: Reporting requirements

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

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at
https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research [Study Advertisement]	3	25 October 2022
Cover Letter		
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University of Sheffield]		
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University of Sheffield]		
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance certificate]	V2	25 October 2022
GP/consultant information sheets or letters [Participant Feedback sheet to contact GP]	1	29 March 2022
IRAS Application Form [IRAS_Form_03112022]		03 November 2022
Letters of invitation to participant [Participant invitation email or letter]	3	01 November 2022
Other [HRA not approved letter]	1	12 May 2022
Other [REC unfavourable opinion letter]	1	12 May 2022
Other [Researchers' response to REC and HRA letters]		
Other [FND hope approval letter]	1	12 July 2022
Other [Epilepsy Action Letter of Support]	1	07 July 2022
Other [University Combined Liability Certificate]	2	25 October 2022
Other [Debrief sheet]	2	18 November 2022
Other [Researcher Response to REC Provisional Opinion Letter]		01 November 2022
Participant consent form [Consent Form]	3	25 October 2022
Participant information sheet (PIS) [Participant Information Sheet]	4	18 November 2022
Referee's report or other scientific critique report [Changes in Protocol following scientific, statistical and ethical reviews]	3	01 November 2022
Research protocol or project proposal [Study Protocol]	3	01 November 2022
Summary CV for Chief Investigator (CI) [CV MR Chief Investigator]	1	01 July 2022
Summary CV for student [Student CV]	1	10 March 2022
Summary CV for supervisor (student research) [Supervisor CV]	1	10 March 2022
Validated questionnaire [Validated Questionnaire Battery]	V3	25 October 2022

Statement of compliance

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

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:
https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 319791 Please quote this number on all correspondence

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

Yours sincerely

pp

Dr Louise Taylor
Chair

Email: southyorks.rec@hra.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: Miss Alessia Dunn

Lead Nation England: approvals@hra.nhs.uk

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Professor Markus Reuber
Consultant Neurologist, Professor of Clinical neurology
The University of Sheffield
Academic Neurology Unit, Royal Hallamshire Hospital
Glossop Road
Sheffield
S10 2JFN/A

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

01 December 2022

Dear Professor Reuber

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Examining the role of shame in seizure disorders**
IRAS project ID:	**319791**
Protocol number:	**V2**
REC reference:	**22/YH/0213**
Sponsor	**Sheffield Teaching Hospitals NHS Foundation Trust**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

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

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

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

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **319791**. Please quote this on all correspondence.

Yours sincerely,
Anna Bannister

Approvals Specialist

Email:approvals@hra.nhs.uk

Copy to: *Miss Alessia Dunn*

Appendix B: Study Advertisement Poster

The University Of Sheffield.

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

Have you been diagnosed with functional seizures or epilepsy? Help us to find out more about these conditions by participating in our study!

Title of project: Examining the role of shame in seizure disorders

Who can take part:

You can take part in this study if you have received a clinical diagnosis of Epilepsy or Functional seizures (also known as Non-Epileptic Attack Disorder / Nonepileptic Seizures or Dissociative Seizures).

What will I have to do if I take part:

In this study we intend to explore how people with seizures cope with shame and how shame may impact on their mental health and seizures. In this study you will be asked to complete a number of self-report questionnaires related to seizures, shame and mental health. It will take approximately 45-60 minutes to complete.

Why should I take part:

You will not derive any direct personal benefit from this study, but the findings of this study would help us to understand better the experiences of people with epileptic and functional seizures. Results of this study could also give initial insights to clinicians about psychotherapeutic interventions may be suitable for people with seizures, which could be further tested in future research.

For more information:

If you would like to read more information about the study, please follow this link:
Include QR code (as generated by Qualtrics survey platform) that will lead participants to Qualtrics survey platform including PIS, consent form, questionnaires and debriefing sheet.

Contact details:

If you have further questions about the study please contact:
Eva Popoluska, Trainee Clinical Psychologist (ClinPsyD)
Address: Clinical Psychology Department, University of Sheffield, Cathedral Court, Vicar Lane, Sheffield, S1 2LT.
Phone: Please leave a message with research officer Amrit Sinha on 0114 2226650 and Eva will return your call. (Mon-Sat, 9am-5pm)
Email: epopoluska1@sheffield.ac.uk

Alternatively, you can contact the research supervisors (Dr Liat Levita, Tel: +44 114 2226651, Email: l.levita@sheffield.ac.uk); Professor Markus Reuber, Tel: +44 114 2268763, Email: m.reuber@sheffield.ac.uk) if you have any further questions.

Appedix C: Participant Information Sheet

PARTICIPANT INFORMATION SHEET

Study title: Examining the role of shame in seizure disorders

We would like to invite you to take part in a research study. Before you decide whether to take part, it is important for you to understand why the research is being done and what it would involve for you. Thank you for reading this information sheet.

What is the purpose of the study?
Shame is an emotion that has been shown to be capable of contributing to mental health difficulties in adulthood. In this study we intend to explore how people with seizures cope with shame and how shame may impact on their mental health and seizures. We are also interested to compare how experiences of shame may be similar or different in people with epileptic or functional seizures (also known as dissociative seizures, nonepileptic attack disorder, and psychogenic non-epileptic seizures). This study should help us to understand people with seizures better and to inform psychotherapeutic interventions for people living with seizures. This study is part of a Clinical Psychology Doctorate (ClinPsyD) project based at the University of Sheffield.

Why am I being asked to take part?
You have been invited to participate in this study because you have been diagnosed with epilepsy or functional seizures.

Who can take part in this study?
To be included in the study, you should be aged 18 or over. You should be able to read and write in English and be able to complete this questionnaire on your own without help. You do NOT need to be a resident of the United Kingdom. However, you must have a diagnosis of epilepsy or functional seizures (also known as non-epileptic attack disorder, dissociative seizures, and psychogenic non-epileptic seizures) that was confirmed by a physician (GP, neurologist or psychiatrist). If you do not match these criteria, you are unable to take part in this research.

Do I have to take part?
No. The study is entirely voluntary, and it is up to you to decide whether to take part. Reading this information sheet, and the consent form on the next page will help you to decide whether you would like to take part. If you do decide to take part, you can type your name in the consent form, and then proceed to the questionnaires. You are free to withdraw at any time, without giving a reason.

What will happen if I take part? What will I have to do?

After reading this information sheet, you can proceed to the next page to read a consent form. If you consent to take part, you can complete a confidential survey on this study platform. The questionnaires in this survey will ask you about your background and diagnosis, so we get a better sense of who you are. You will then be asked to fill in a questionnaire battery including seven brief questionnaires. These questionnaires will explore your seizure frequency and severity, coping with shame (two questionnaires), anxiety, depression, and somatic symptoms. Access to a computer and a reliable internet connection will be required to complete these questionnaires; this will take approximately one hour. If you need to pause or leave the survey, you can return to it by using the same link on the same device that you started the survey with.

What are the possible disadvantages and risks of taking part?
There are no major risks associated with this study. However, the questionnaires include measures of seizures, anxiety, depression, shame, and somatic symptoms. These topics may touch on sensitive topics for some people. There will be an optional grounding exercise at the end of the survey that can help people to feel calmer after the study. If you have concerns about your mood, please take action as follows:

- Please get in touch with your GP service. They can offer you assessment and advice about mental health difficulties and signpost you to relevant services.
- If you are in a crisis, you should contact emergency services (in the UK call 111 or 999).
- If you live in the UK and have thoughts about harming yourself, please contact the Samaritans on telephone number 116 123. This is a free line that is available 24 hours a day.
- If you do not live in the UK, please see this website to find your national mental health support lines: Helplines, Suicide Hotlines, and Crisis-Lines from Around the World

What are the possible benefits of taking part?
There are no immediate benefits for people participating in the project. However, it is hoped that this study will help us to better understand the experiences of people with epilepsy and functional seizures. Results of this study could also give initial insights to clinicians about what psychotherapeutic interventions may be suitable for people with seizures, which could be further tested in future research.

How will we use information about you?
We will need to use information from you for this research project.

This information will include your name and email address. This will be stored separately from the information you provide by answering the questionnaires. We will use your contact details to inform you if your responses to the questionnaires indicate that you may have clinical levels of depressive or anxiety symptoms, warranting further assessment by your GP. We will let you know this by letter sent just to yourself. We will also use these details to offer participants a summary of the study outcome. You can opt in or out of this. Otherwise, your personal data/medical records and data files may only be used for checks by regulatory authorities and the Sponsor of the research (The University of Sheffield and Sheffield Teaching Hospital) to make sure that we have followed all rules about how research should be carried out. Your data will be always kept confidential.

People who do not need to know who you are will not be able to see your name or contact details. When we analyse your data, it will be identified by a study number rather than your name or other personal data.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?
You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

The data collected in this study will not be used in future research.

Where can you find out more about how your information is used?

You can find out more about how we use your information:

- at www.hra.nhs.uk/information-about-patients/
- at https://www.sheffieldclinicalresearch.org/for-patients-public/how-is-your-information-handled-in-research/
- at Patient Data and Research leaflet - Health Research Authority (hra.nhs.uk)
- by contacting the research team via the contact details indicated at the end of this document.

You can also read the following section about what happens with your data in the study in detail:

The Sheffield Teaching Hospital National Health Fundation Trust (STH NHSFT) will act as the Sponsor and Joint Data Controller for this study. The University of Sheffield will also act as a joint data controller. This means, that we will be responsible for looking after your information and using it properly. All your data will be stored securely in password protected files at a secured University of Sheffield data drive, accessible only to members of the research team. After the completion of the study, the University of Sheffield will archive all the study documents for 10 years, and then securely dispose them. All information collected during this study will be kept confidential.

If you are recruited via Sheffield Teaching Hospitals NHS FT (STH NHSFT), members of your direct clinical team may use your name, NHS number and contact details to contact you about the research study. You will be contacted by the research team only if you give them permission to do so. The researchers in this study will have no access to your clinical records unless you are under their care at the STH.

Your data will be pseudo-anonymous. This means that your study number can be used to link your survey answers and your personal details. This will allow us to email you to advise you to get in touch with your GP if your scores on the questionnaires indicate clinically significant anxiety and depression. When data-analysis commences, your personal data

(e.g. email address, name) will be separated from your questionnaire data and stored in separate files. Your questionnaire data will be assigned a study participant ID, so researchers will not be able to identify you when performing statistical analysis. You will not be identified in any reports or publications.

When you complete the online survey, your computer IP address will be recorded. This helps us to remove those participants who complete the study more than once. After the data will be screened to delete duplicate participant responses, all the recorded IP addresses will be permanently deleted.

All your data will be managed according to the latest General Data Protection Regulation (GDPR) laws. For more information, please see: Patient Data and Research leaflet - Health Research Authority

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). As we will be collecting some data that is defined in the legislation as more sensitive (i.e. information about your ethnic origin and health), we also need to let you know that we are applying the following condition in law: that the use of your data is 'necessary for scientific or historical research purposes'.

The results of this study will form part of a Clinical Psychology Doctoral thesis. We also aim to publish the results in an academic journal. As stated above, you will not be personally identified in any reports or publications.

You can opt in to receive the results of this study by giving researchers consent to email you about a summary of the study results and if you win one £25 vouchers of the study lottery. We will not contact you about these without your consent.

Who is organising and funding the research?
This study is being conducted by Eva Popoluska (Trainee Clinical Psychologist), as part of the qualification towards becoming a Doctor of Clinical Psychology at the University of Sheffield. Eva is being supervised by Professor Markus Reuber and Dr. Liat Levita, who are also based at the University of Sheffield. The research is being carried out in collaboration with the National Health Service (NHS), specifically the Neurology Department based at Sheffield Teaching Hospitals NHSFT. The study is funded by the University of Sheffield.

Who has ethically reviewed the project?
All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the Yorkshire and the Humber – South Yorkshire Committee.

What if something goes wrong and I wish to complain about the research?
If you would like to make a complaint about this project, in the first instance you should contact the lead researcher or their supervisor. If you do not feel satisfied that your complaint has been dealt with appropriately you can contact Sheffield Patient Services Team on 0114 2712400 or email: STH.PALS@nhs.net. You can also contact the Sheffield Teaching Hospitals NHS Foundation Trust Patient partnership team at address: Patient partnership

department, B floor, Royal Hallamshire Hospital, Glossop Road, Sheffield S10 2JF. Tel: 0114 2712450.

If your complaint relates to how your personal data has been handled, additional information about how to raise a complaint can be found in the University's Privacy Notice and you can contact the information governance team at STH via email: sth.infogov@nhs.net

If you have further questions about the study, please feel free to contact the research team on the contact details below.

Contact Details

Lead researcher
Name: Eva Popoluska
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Telephone: Please leave a message with research officer Amrit Sinha on 0114 2226650 and Eva will return your call.

First Supervisor
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Thank you very much for taking time to read about the project.

Appendix D: Consent Form

The University Of Sheffield.

Sheffield Teaching Hospitals NHS
NHS Foundation Trust

ONLINE CONSENT FORM

Examining the role of shame in seizure disorders

	Please tick the appropriate boxes	**Yes**	**No**
1.	I confirm that I have read and understand the information sheet (version 3, 18.10.2022) for the above study and fully understand what is expected of me within this study.		
2.	I confirm that I have had the opportunity to ask questions and to have them answered.		
3.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights been affected. I understand that the researchers will keep the information about me that they already have.		
4.	I understand my personal details (e.g. name, email address) will be not be revealed to people outside the project. I understand that regulatory authorities or representatives the Sponsor (Sheffield Teaching Hospitals NHS FT or University of Sheffield) may inspect data files or my medical records/personal data to ensure researchers adhered to data regulations. I give permission for these individuals to access my data. I understand that my data will be kept confidential at all times.		
5.	I agree to take part in the above study and understand that the data will be used as part of a Clinical Psychology Doctorate degree thesis.		
6.	I give my consent to the researchers to contact me if my scores are in the clinically significant level on the anxiety and/or depression questionnaires.		
7.	I understand that my computer IP address will be recorded when completing the survey. I also understand that my IP address will be permanently deleted once duplicate respondents are removed from the study.		
8.	I confirm that I understand the above points and give my consent to participate in this study.		
	Optional consent:		
9.	I give my consent to the researcher to email me the summary of study results.		

Full name of participant: Date:

Appendix E: Diagnostic Screening Questionnaire

Please give us an honest and accurate answer to these questions. The information you are giving us will be treated as confidential.

1. **Do you have one of these conditions?**
   - □ Epilepsy
   - □ Functional seizures
   - □ Both epilepsy and functional seizures
   - □ None of the above

2. **Was this diagnosis confirmed by a physician (psychiatrist, neurologist, or GP)?**

   - □ Yes
   - □ No

3**. Are you receiving treatment for any mental health problems?** *(Select all that apply)*

   - □ Anxiety
   - □ Depression
   - □ Post-traumatic Stress Disorder
   - □ None
   - □ Other (please specify)

Appendix F: Optional Grounding Exercise

Please consider taking a couple of minutes to help you to ground yourself after this survey. Grounding exercises can help us to feel calmer, reduce stress, and reconnect to our surroundings.

Please click on the link below, if you would like to take part in a 3 minutes grounding exercise:

https://www.youtube.com/watch?v=1ao4xdDK9iE

There is an option to turn on subtitles in the video.

Appendix G: Debriefing Sheet

Debriefing sheet

Thank you for taking the time to participate in this study.

If you have any questions or concerns please do not hesitate to contact Eva Popoluska (Email: epopoluska1@sheffield.ac.uk).

Also feel free to also contact the research supervisors (Dr Liat Levita, Tel: +44 (0)1273 075469, Email: l.levita@sussex.ac.uk); Professor Markus Reuber, Tel: +44 114 2268763, Email: m.reuber@sheffield.ac.uk) if you have any further questions.

If you wish to make a complaint or have any concerns and do not want to speak to the researcher team, you can contact Sheffield Patient Services Team on 0114 2712400. Email STH.PALS@nhs.net or you can contact Sheffield Teaching Hospitals NHS Foundation Trust Patient partnership team at: Patient partnership department, B floor, Royal Hallamshire Hospital, Glossop Road, Sheffield S10 2JF. Tel: 0114 2712450.

If you have concerns about your mood, please take action as follows:

- Please get in touch with your **GP service**. They can offer you assessment and advice about mental health difficulties and signpost you to relevant services.
- If you are in a crisis, you should contact **emergency services** (in the UK call 111 or 999).
- If you live in the UK and have thoughts about harming yourself, please contact the **Samaritans** on telephone number 116 123. This is a free line that is available 24 hours a day.
- If you do not live in the UK, please see this website to find your **national mental health support lines**: Helplines, Suicide Hotlines, and Crisis-Lines from Around the World
- You can also contact **Mind**, for non-urgent advice and support on mental health difficulties. Mind Infoline: 0300 123 3393 (Lines open 9am - 6pm, Monday to Friday) or email: info@mind.org.uk

For more information:

- **about Functional Seizures please visit: https://fndhope.org**
- **about Epilepsy please visit: https://www.epilepsy.org.uk**

Appendix H: Measures

Demographics

Please answer the following questions about yourself.

The information you are giving us will be treated as confidential. Personally identifiable data (such as your name, address and date of birth) will not be stored and analysed together with the data provided on the self-report questionnaires.

Q15 What's your full name?

_____

Q16 How old are you?

_____

Q16 Where are you located? (Country)

_____

Q18 What is your email address?

_____

Q19 Are you?:

o Male (1)

o Female (2)

o Other (please specify) (3)

_____

Q20 How would you describe your ethnic background?

- o Any Asian background (1)
- o Any Black background (2)
- o Any White background (3)
- o Any Mixed/Multiple Ethnic group (4)
- o Any other ethnic group (please specify) (5)

_____

Q21 How would you describe your current employment status?

- o In any paid work (1)
- o In full-time education (2)
- o A Full-time carer/homemaker (3)
- o On leave/out of work due to illness or disability (4)
- o Retired (5)
- o Other (please specify) (6)

_____

Q22 What is your highest educational qualification? Do you have:

- o No educational qualifications (1)
- o Primary/Elementary Education (2)
- o Secondary/High School Education (3)
- o Trade or Vocational Education (4)

- o Post-secondary Certificate/Diploma (5)
- o Higher Education Degree (e.g. BA/BSc) (6)
- o Post-graduate qualification (e.g. MSc/PhD) (7)
- o Professional qualification (8)
- o Other (please specify) (9)

Perceived Socioeconomic status (Adler et al., 2000)

Think of this ladder as showing where people stand in their communities.

People define community in different ways. Please define it in whatever way is most meaningful to you.

At the top of the ladder are the people who have the highest standing in their community.

At the bottom are the people who have the lowest standing in their community.

Where would you place yourself on this ladder?

Place an **X** on the rung where you think you stand at this time of your life relative to other people in your community.

Position the slider below where you think you stand at this time in your life compared to other people in your community:

1 2 3 4 5 6 6 7 8 9 10

Test of Self-Conscious Affect Scale (TOSCAS-3; Tangney et. al., 2000)

TOSCA-3
Short Version

Below are situations that people are likely to encounter in day-to-day life, followed by several common reactions to those situations.

As you read each scenario, try to imagine yourself in that situation. Then indicate how likely you would be to react in each of the ways described. We ask you to rate all responses because people may feel or react more than one way to the same situation, or they may react different ways at different times.

For example:

A. You wake up early one Saturday morning. It is cold and rainy outside.

a) You would telephone a friend to catch up on news. 1---2---3---4---5
not likely very likely

b) You would take the extra time to read the paper. 1---2---3---4---5
not likely very likely

c) You would feel disappointed that it's raining. 1---2---3---4---5
not likely very likely

d) You would wonder why you woke up so early. 1---2---3---4---5
not likely very likely

In the above example, I've rated ALL of the answers by circling a number. I circled a "1" for answer (a) because I wouldn't want to wake up a friend very early on a Saturday morning -- so it's not at all likely that I would do that. I circled a "5" for answer (b) because I almost always read the paper if I have time in the morning (very likely). I circled a "3" for answer (c) because for me it's about half and half. Sometimes I would be disappointed about the rain and sometimes I wouldn't -- it would depend on what I had planned. And I circled a "4" for answer (d) because I would probably wonder why I had awakened so early.

Please do not skip any items -- rate all responses.

1. You make plans to meet a friend for lunch. At 5 o'clock, you realize you stood him up.

a) You would think: "I'm inconsiderate." 1---2---3---4---5 not likely very likely

b) You would think: "Well, they'll understand." 1---2---3---4---5 not likely very likely

c) You'd think you should make it up to him as soon as possible. 1---2---3---4---5 not likely very likely

d) You would think: "My boss distracted me just before lunch." 1---2---3---4---5 not likely very likely

2. You break something at work and then hide it.

a) You would think: "This is making me anxious. I need to either fix it or get someone else to." 1---2---3---4---5 not likely very likely

b) You would think about quitting. 1---2---3---4---5 not likely very likely

c) You would think: "A lot of things aren't made very well these days." 1---2---3---4---5 not likely very likely

d) You would think: "It was only an accident." 1---2---3---4---5 not likely very likely

3. At work, you wait until the last minute to plan a project, and it turns out badly.

a) You would feel incompetent. 1---2---3---4---5 not likely very likely

b) You would think: "There are never enough hours in the day." 1---2---3---4---5 not likely very likely

c) You would feel: "I deserve to be reprimanded for mismanaging the project." 1---2---3---4---5 not likely very likely

d) You would think: "What's done is done." 1---2---3---4---5 not likely very likely

4. You make a mistake at work and find out a co-worker is blamed for the error.

a) You would think the company did not like the co-worker. 1---2---3---4---5 not likely very likely

b) You would think: "Life is not fair." 1---2---3---4---5 not likely very likely

c) You would keep quiet and avoid the co-worker. 1---2---3---4---5 not likely very likely

d) You would feel unhappy and eager to correct the situation. 1---2---3---4---5 not likely very likely

5. While playing around, you throw a ball and it hits your friend in the face.

a) You would feel inadequate that you can't even throw a ball. 1---2---3---4---5 not likely very likely

b) You would think maybe your friend needs more practice at catching. 1---2---3---4---5 not likely very likely

c) You would think: "It was just an accident." 1---2---3---4---5 not likely very likely

d) You would apologize and make sure your friend feels better. 1---2---3---4---5 not likely very likely

6. You are driving down the road, and you hit a small animal.

a) You would think the animal shouldn't have been on the road. 1---2---3---4---5 not likely very likely

b) You would think: "I'm terrible." 1---2---3---4---5 not likely very likely

c) You would feel: "Well, it was an accident." 1---2---3---4---5 not likely very likely

d) You'd feel bad you hadn't been more alert driving down the road. 1---2---3---4---5 not likely very likely

7. You walk out of an exam thinking you did extremely well. Then you find out you did poorly.

a) You would think: "Well, it's just a test." 1---2---3---4---5 not likely very likely

b) You would think: "The instructor doesn't like me." 1---2---3---4---5 not likely very likely

c) You would think: "I should have studied harder." 1---2---3---4---5 not likely very likely

d) You would feel stupid. 1---2---3---4---5 not likely very likely

8. While out with a group of friends, you make fun of a friend who's not there.

a) You would think: "It was all in fun; it's harmless." 1---2---3---4---5 not likely very likely

b) You would feel small...like a rat. 1---2---3---4---5 not likely very likely

c) You would think that perhaps that friend should have been there to defend himself/herself. 1---2---3---4---5 not likely very likely

d) You would apologize and talk about that person's good points. 1---2---3---4---5 not likely very likely

9. You make a big mistake on an important project at work. People were depending on you, and your boss criticizes you.

a) You would think your boss should have been more clear about what was expected of you. 1---2---3---4---5 not likely very likely

b) You would feel like you wanted to hide. 1---2---3---4---5 not likely very likely

c) You would think: "I should have recognized the problem and done a better job." 1---2---3---4---5 not likely very likely

d) You would think: "Well, nobody's perfect." 1---2---3---4---5 not likely very likely

10. You are taking care of your friend's dog while they are on vacation and the dog runs away.

a) You would think, "I am irresponsible and incompetent."	1---2---3---4---5 not likely very likely
b) You would think your friend must not take very good care of their dog or it wouldn't have run away.	1---2---3---4---5 not likely very likely
c) You would vow to be more careful next time.	1---2---3---4---5 not likely very likely
d) You would think your friend could just get a new dog.	1---2---3---4---5 not likely very likely

11. You attend your co-worker's housewarming party and you spill red wine on their new cream-colored carpet, but you think no one notices.

a) You think your co-worker should have expected some accidents at such a big party.	1---2---3---4---5 not likely very likely
b) You would stay late to help clean up the stain after the party.	1---2---3---4---5 not likely very likely
c) You would wish you were anywhere but at the party.	1---2---3---4---5 not likely very likely
d) You would wonder why your co-worker chose to serve red wine with the new light carpet.	1---2---3---4---5 not likely very likely

Shame-Aversive Reactions Questionnaire (ShARQ, Shoenleber & Berenbaum, 2010)

Please read the following statements and indicate how much you agree or disagree with each item along the 7-point scale below.

Strongly Disagree *Nor Agree* *Neither Disagree* *Strongly Agree*

1 ---------- 2 ---------- 3 ---------- 4 ---------- 5 ---------- 6 ---------- 7

_____ 1) It bothers me to think that I might be inferior to others.

_____ 2) I am comfortable acknowledging my imperfections.

_____ 3) I tend to keep away from situations in which I may feel incompetent.

_____ 4) I simply cannot stand to be ridiculed by others.

_____ 5) I am rarely troubled when my own shortcomings are exposed to me.

_____ 6) I can still feel comfortable even if I appear somewhat incompetent.

_____ 7) I am rarely concerned that I will be disgraced in public.

_____ 8) I always try to avoid situations in which I may be ridiculed by others.

_____ 9) It usually doesn't hurt me to feel like I am personally flawed.

_____ 10) I am generally not distressed when my defects are pointed out to me.

_____ 11) Feeling inadequate troubles me more than anything else.

_____ 12) I rarely dwell on how likely it is that I will feel inferior.

_____ 13) I am constantly concerned that I could be humiliated.

_____ 14) The most painful experience for me is when I recognize my own defects.

***Liverpool Seizure Severity Scale** (LSSS-2, Scott-Lennox et al. 2001)*

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 am doing in:	Less than 1 minute	0	Between 1 and 5 minutes	1	Between 6 minutes and 1 hour	2	1 to 2 hours	3	More than 2 hours	4	

Seizure frequency scale (developed by Prof Markus Reuber)

Please tick the box which best describes the frequency of your seizures over the last year:

1) I usually have more than one seizure per day.

2) I usually have more than one seizure per week but fewer than one seizure per day.

3) I usually have more than one seizure per month but fewer than one seizure per week.

4) I usually have more than one seizure per year but fewer than one seizure per month.

5) I have not had any seizures in the last year.

***Patient Health Questionnaire** (PHQ-8; Kroenke et. al, 2001)*

SMRC
Self-Management
Resource Center

Personal Health Questionnaire Depression Scale (PHQ-8)

Over the **last 2 weeks**, how often have you been bothered by any of the following problems?
*(circle **one** number on each line)*

How often during the past 2 weeks were you bothered by...	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself, or that you are a failure, or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3

Generalized Anxiety Disorder scale (GAD-7; Spitzer et al., 2006)

Generalised Anxiety Disorder 7-item (GAD-7) scale

Name: _____ Date of Birth: _____

GP _____ Date Completed: _____

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

Total Score (*add your column scores*) =

Somatic Symptom Scale (SSS-8; Gierk et. al. 2014)

Somatic Symptom Scale – 8 (SSS-8)

During the past 7 days, how much have you been bothered by any of the following problems?					
	Not at all	A little bit	Somewhat	Quite a bit	Very much
Stomach or bowel problems	0	1	2	3	4
Back pain	0	1	2	3	4
Pain in your arms, legs, or joints	0	1	2	3	4
Headaches	0	1	2	3	4
Chest pain or shortness of breath	0	1	2	3	4
Dizziness	0	1	2	3	4
Feeling tired or having low engery	0	1	2	3	4
Trouble sleeping	0	1	2	3	4

Appendix H: Regression Models with Partial and Semi-partial Correlations

Table 6

Regression Analyses of Group membership as Moderator of the Relation Between Shame Aversion and Shame Proneness and Seizure Severity and Seizure Frequency

Predictor	ΔR^2	ΔF	*Beta [95%CI]*	*Correlations*	
				Partial	*Semi-partial*
1. Depression as dependent variable					
Step 1	.20	F (3, 132)=11.5**			
Age			-.08 [-.14, .05]	-.09	-.08
Gender			.02 [-.37,.50]	.03	.02
Perceived SES			-.44 [-.59, -.28]**	-.44	-.43
Step 2	.37	F (6, 129) =12.73**			
SP			.07 [-.13, .26]	.06	.05
SA			.39 [.21, .58]**	.35	.29
Group			.24 [.19, .79]**	.27	.22
Step 3	.38	F (8, 127)=9.69**			
SP * group			-.12 [-.57, .20]	-.08	-.07
SA * group			.00 [-.37, .37]	.00	.00
2. Anxiety as dependent variable					
Step 1	.07	F (3, 132)=3.33*			
Age			-.14[.31, -.03]	-.14	-.14
Gender			-.01 [-.49, .44]	-.01	-.01
Perceived SES			-.26[-.39, -.06]**	-.22	-.22
Step 2	.31	F (6, 129)=9.69**			
SP			.15 [-.06, .35]	.13	.10
SA			.47 [.28, .67]**	.39	.36
Group			.14 [-.03, .60]	.16	.13
Step 3	.31	F (8, 127)=7.20**			
SP * group			-.07 [-.48, .30]	-.04	-.03
SA * group			.02 [-.38, .44]	.01	.01
3. Somatization as dependent variable					
Step 1	.16	F (3, 132)= 8.240**			
Age			-.01 [-.17,.16]	-.01	-.01
Gender			.00[-.43,.45]	.00	.00
Perceived SES			-.40[-.55,-.23]**	-.39	-.39
Step 2	.29	F (6, 129)= 8.665**			
SP			.13[-.08, .33]	.11	.09
SA			.15 [-.04, .34]	.13	.11
Group			.36[.39,1.02]**	.36	.33
Step 3	.30	F (8, 127)= 6.691**			
SP * group			.11 [-.23, .60]	.08	.06
SA * group			-.19 [-.65, .14]	-.11	-.01

Note. SES = Socioeconomic Status; SA = Shame aversion; SP=Shame proneness. Gender is dummy coded variable, with male d=0 and female d=1. *p< .05 **p<. 01

Table 7

Regression Analyses of Group Membership as Moderator of the Relation Between Shame Aversion and Shame Proneness and Seizure Severity and Seizure Frequency

Predictors	ΔR^2	ΔF	*Beta (95% CI)*	*Correlations*	
				Partial	*Semi-partial*
1. Seizure severity as dependent variable					
Step 1	.10	F (3, 89)= 2.97*			
Age			-.23 [-.44, -.02]*	-.23	-.22
Gender			-.22 [-1.13,-.03]*	-.21	-.21
Perceived SES			-.15 [-.37,.05]	-.16	-.15
Step 2	.20	F (6, 86)= 3.68**			
SP			-.04 [-.32,.24]	-.03	-.03
SA			.15 [-.11,.41]	-12	.11
Group			-.32 [-1.07,-.23]**	-.32	-.30
Step 3	.22	F (8, 84)= 2.97**			
SP * group			-.22 [-.84,.21]	-.13	-.11
SA * group			.26 [-.19, .84]	.04	.13
2. Seizure frequency as dependent variable					
Step 1	.11	F (3, 132)= 6.03**			
Age			.04 [-.13, .20]	.04	.04
Gender			-.08[-.67,.23]	-.08	-.08
Perceived SES			-.37[-.53, -21]**	-.36	-.36
Step 2	.28	F (6, 129)= 9.537**			
SP			.00 [-.20, .21]	.00	.00
SA			-.11 [-.30,.09]	-.10	-.09
Group			.41[.51; 1.14]**	.41	.38
Step 3	.27	F (8, 127)= 7.202**			
SP * group			.02[-.37,.45]	.02	.01
SA * group			.09[-.27, .51]	.05	.04

Note. SES = Socioeconomic Status; SA = Shame aversion; SP=Shame proneness. Gender is dummy coded variable, with male d=0 and female d=1.

*p< .05 **p<. 01