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Doctoral Thesis

A meta-synthesis of stigma in epilepsy, and an empirical exploration of self-disgust in epilepsy

Rebecca Mayor

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Word Count

	Main text	Appendices (inc. tables, references, abstracts, footnotes and title pages)	Total
Thesis Abstract	279	0	279
Literature Review	7973	9366	17339
Research Paper	7978	10133	18111
Critical Appraisal	3986	891	4877
Ethics Section	3845	8382	12227
Total	24,061	28,772	52,833

Thesis Abstract

Section one of this thesis describes a meta-ethnographic approach to the synthesis of 24 qualitative studies exploring the experiences of stigma in adults with epilepsy across the globe. Five themes were generated: societal negative perceptions of epilepsy result in discrimination and rejection; internal attributions of blame lead to negative self-perception and shame; impact of stigma on everyday life and associated reliance on others; attempts to manage stigma through concealment and avoidance; support from others is beneficial but dependent on own and others' understandings of epilepsy. The synthesis highlighted the key individual experiences of epilepsy stigma, which appeared to be to some degree culturally specific. Culturally informed misconceptions of epilepsy were readily internalised which resulted in emotional challenges for participants and impacted on participants' lives.

Section two provides an empirical report of a qualitative exploration into the experiences of self-disgust in adults with epilepsy. Three key themes were identified from analysis of the data: being an outsider, "the feeling of being a bit of a freak;" the inescapable presence of self-disgust, "it's a niggling feeling that something's not quite right" and preventing exposure, "living a protected life." People with epilepsy experienced disgust in reaction to the physical symptoms of seizures and these disgust-based feelings appeared to become internalised following others' disgust reactions. Avoidance as a strategy to manage self-disgust can be protective but may inadvertently maintain self-disgust.

Section three provides a critical appraisal of the thesis. This offers a reflective account of the experiences of developing and conducting this research and some of the strengths and weaknesses of the research. The potential implications for clinical practice and future research are discussed, as well as personal reflections of the research process.

Declaration

This thesis documents research undertaken between September 2016 and August 2020, in partial fulfilment of the Lancaster University Doctorate in Clinical Psychology. The work presented here is my own, except where due reference has been made. This thesis has not been submitted for the award of a higher degree elsewhere.

Signature:

Print name: Rebecca Mayor

Date: 23/12/2020

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Firstly, I would like to thank all of the people who took part in this research. Without their time it would not have been possible to complete this work. I would also like to thank the clinicians and epilepsy charity, Epilepsy Action, for their support in the recruitment to this study.

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Contents

Section One: Literature Review

Experiences of stigma in people with epilepsy: a meta-synthesis of qualitative evidence

Rebecca Mayor

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

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All correspondence should be addressed to:

Rebecca Mayor
Doctorate in Clinical Psychology
Division of Health Research, Furness College
Lancaster University
Lancaster
LA1 4YF
Tel: +44 1524 592970
Fax: +44 1524 592981
Email: R.Mayor@lancaster.ac.uk

Abstract

Objective: Stigma is reported to cause as much distress and effect on the quality of life of individuals with epilepsy as the physical symptoms of seizures. Existing quantitative reviews have focused on describing levels of stigma in epilepsy, but no qualitative review has been currently undertaken despite the increasing number of studies in this area. In attempt to understand the experiences of stigma in adults with epilepsy across different sociocultural contexts, this review reports the results of a qualitative synthesis.

Methods: A systematic database search was conducted. The search strategy yielded an initial set of 2,877 relevant papers, of which 24 were included. A meta-synthesis was conducted according to the meta-ethnographic approach described by Noblit and Hare (1988) adapted for health research by Britten et al. (2002).

Results: Five themes were generated: societal negative perceptions of epilepsy result in discrimination and rejection; internal attributions of blame lead to negative self-perception and shame; impact of stigma on everyday life and associated reliance on others; attempts to manage stigma through concealment and avoidance; support from others is beneficial but dependent on own and others' understandings of epilepsy. These themes highlighted the key individual experiences of epilepsy stigma, which appeared to be to some degree culturally specific. Culturally informed misconceptions of epilepsy were readily internalised which resulted in emotional challenges and impacted on participants' lives. Strategies for coping with this were described.

Significance: The synthesis demonstrated the experiences of stigma in adults with epilepsy and highlighted some of the key similarities and differences in these experiences across sociocultural contexts. Educational programmes to inform communities about epilepsy continue to have relevance.

Keywords: Seizures, Discrimination, Experiences, Qualitative

Epilepsy has recently been re-defined to aid clinical usage and understandings of the condition[1] (see Appendix 1-A). As such, it is understood that there are many different types of epileptic seizures and epilepsy is viewed as a heterogenous condition in terms of cause, severity and consequences. As such, having a persistent condition characterised by an increased risk of experiencing unprovoked seizures has multifaceted implications for the lives of individuals with the condition beyond the impact of acute seizures themselves.[2] Therefore, people with epilepsy who continue to experience seizures are more likely to report negative consequences of the condition than those who are seizure free.[3] People with epilepsy are reported to experience difficulties in their lives as a result of cognitive, emotional and psychological factors.[4] Thus, having epilepsy can impact on levels of anxiety, depression and self-esteem, as well as social and leisure opportunities and family functioning.[5] People with epilepsy experience social and legal restrictions on their lives, in relation to driving[6] and employment,[7] which may have additional implications for their welfare.

One factor which has been consistently found to be negatively associated with psychosocial wellbeing in people with epilepsy is stigma. Stigma may cause as much distress and affect the quality of life of individuals with epilepsy as the physical symptoms associated with the condition.[8] As such, higher levels of perceived stigma have been found to correlate with more anxiety[9] and depression[5] and low self-esteem in people with epilepsy.[10]

The term ‘stigma’ originated in the Greek word used to indicate the marks made on skin to indicate a negatively valued person within society, such as a thief or slave. More recently, stigma has been described as “an attitude that is deeply discrediting.”[11 (p.3)] Goffman, one of the first theorists on stigma from a sociological perspective, emphasised the importance of societal norms in the development of stigma. He proposed that those who

deviate from these norms are viewed as "not quite human"[11 (p.5)] and, therefore, legitimate targets for social exclusion. Link and Phelan[12] further conceptualised stigma as a co-occurrence of distinct components; individuals with differences are labelled as separate and linked to negative stereotypes, which leads to social separation and distancing, resulting in loss of status and discrimination. They further argued that for stigma to exist, social power must be exercised. Those who hold status are, therefore, entitled in imposing their negative appraisals, disapproval and rejection of socially different others. Moreover, they argued that stigma would likely be a significant factor in affecting the life chances of individuals who experience it. Stigmatised groups are, therefore, likely to experience difficulties in quality of life including social relationships, health, employment and educational outcomes.[13]

Within health research, the conceptualisation of stigma has been extended to include anticipated stigma, along with enacted and internalized (or felt) stigma.[14] Anticipated stigma can be understood as the degree to which individuals expect to receive discrimination or social rejection. Enacted stigma is defined by the active discrimination experienced in the past, and internalized or felt stigma as the feelings associated with the internalisation of the reactions or beliefs of others.[15,12] All three forms of stigma may be associated with poorer physical and psychological outcomes[16] and may also have a deleterious impact on health behaviours.[17]

Individuals with epilepsy are likely to have been at increased risk of experiencing stigma since the time when it was associated with the supernatural and contagion.[18] Since the late 19th century, significant advances in the scientific understanding of epilepsy have been made. However, misunderstandings about epilepsy and discrimination of people with the condition have persisted.[19] Indeed, until a recent campaign for change, the wording for

epilepsy in China (dian xien) linked the disorder with 'madness' and the literal translation of epilepsy in Cambodia (Chhkourt chrouk) is 'mad pig disease.'[20]

Models of stigma in epilepsy have, therefore, been proposed which aim to improve understanding regarding stigma within this specific population. Similar to those described in the wider stigma literature, these have described the experiences of discrimination and the internalisation of these negative interactions.[21,22] However, how individuals with epilepsy experience stigma may differ across cultures. More examples of enacted stigma in poorer, less resourced countries have been reported.[23] In contrast, in a study conducted in Europe,[24] results indicated little evidence of overt discrimination, but significant levels of perceived stigma.[24] Furthermore, the authors concluded that levels of stigma were not related to the frequency or severity of seizures, but that stigma may be based solely on the label of epilepsy.[25] In keeping with this emphasis on the importance of the social construction of epilepsy, the authors described significant differences in levels of epilepsy stigma between countries.[24]

Further, negative beliefs and lack of knowledge about epilepsy have even been described in those providing health care in some countries.[26,27] In addition, evidence suggests that, across the globe, epilepsy continues to be misrepresented in the media.[28] A study exploring how epilepsy is portrayed by people with and without seizures on the social media platform, Twitter suggested that 41% of comments were derogatory.[29] As a result, considerable effort has been invested in improving awareness of epilepsy across the world.[30] However, despite this, recent reviews evaluating the impact of intervention studies aimed at reducing epilepsy stigma suggest that this remains.[19, 31]

A recent review of studies investigating stigma in epilepsy, reported that quantitative questionnaire studies may fail to identify some more subtle forms of stigma.[19] Indeed, in a

mixed methods review, it was concluded that adolescents did not report experiencing stigma on questionnaire measures but, on further exploration using qualitative methods, participants described keeping their epilepsy a secret.[32] Therefore, qualitative studies may further uncover these more subtle beliefs and behaviours.

Previous reviews have explored the qualitative literature in relation to experiences of stigma in children with epilepsy[33] and their families.[34] However, there may be distinct factors that influence stigma in adults with epilepsy that are not relevant to children, for example, the concept of marriage and employment. One recent meta-synthesis considered the experiences of adults with epilepsy.[35] However, the scope of the review was small, describing the experiences of people in particular countries (Africa, Asia, Eastern Europe and Latin America) and focusing on perceptions of causes and treatments for epilepsy.

Research thus far has, therefore, highlighted the importance of stigma in the quality of life and lived experience of people with epilepsy.[36] However, while quantitative reviews have offered information about this in numeric terms, these are not designed to deliver the sort of richly detailed description of stigma which qualitative research can offer. In addition, due to the importance of socio-cultural factors in the experience of stigma in individuals with epilepsy, individual qualitative studies in this area and meta-syntheses so far have been limited by the setting and group of patients they have recruited. A meta-synthesis of qualitative studies in adults with epilepsy across cultures, therefore, provides a means of seeking and highlighting themes which come out across different studies and which may give some new insights into what it is like to live with epilepsy.

Method

Search strategy

Two systematic literature searches were conducted; an original search conducted in January 2017 and an updated search in May 2019. Abstract and Title fields (or Abstract/Title for PubMed) of the databases PubMed, PsycINFO, Scopus and CINAHL were searched for appropriate articles. Following consultation with an academic librarian and in order to conduct the most comprehensive search possible, the search strategy included separate searching of key search terms and thesaurus entries or Medical Subject Headings (MeSH) for the major concepts of epilepsy, stigma and experiences (except for the Scopus database which does not endorse a thesaurus). Search terms and thesaurus entries were then combined with the Boolean operator 'OR' for each concept. Finally, the three concepts were then combined with 'AND' to provide the final search results. To complete as robust a search possible and prevent any articles being missed, reference lists of included papers were hand searched, citation searches of included articles were conducted and Table of Contents from relevant journals, for example Epilepsy & Behaviour, were also searched. Full details of the searches conducted can be found in Appendix 1-B.

Studies were screened for inclusion in the review, according to the criteria described in Table 1. As there has been no previous meta-synthesis in this area, no time restriction was applied.

- Insert Table 1 about here -

Search results were reviewed in the citation software Endnote X9. Duplicates were removed. Titles and abstracts of studies identified by the literature search were screened and those which did not meet inclusion/exclusion criteria (for example, studies not on human populations or not epilepsy research) excluded. Whenever it was uncertain whether all inclusion criteria were met, full text articles were retrieved and further considered. The 74

full text articles were reviewed by the author. For example, the full article by Aydemir and colleagues[37] was excluded at this stage as the views of family members were included in the analysis, with no distinct separation. Where there was uncertainty about inclusion (n = 12), this was discussed with a co-coder (another trainee clinical psychologist) and a final decision agreed. For example, a study by Kilinc and colleagues was excluded on the basis that there was no direct reference made regarding stigma or discriminatory experiences in the article abstract.[38]

Selected studies

A flow chart of the search process is provided in Figure 1. Of a total of 2,877 publications identified by the literature searches, 24 were found to be eligible for inclusion in the review. Sixteen articles reported on original research samples. Four groups of authors described a single study sample in two separate publications but were included in this review as they focused on different research questions and thus provided complementary information (n = 8).[39-46]

- Insert Figure 1 about here -

The following data were extracted from each eligible study: author(s), date of publication, title of article, data collection method and method of analysis, sample size, population (including type of epilepsy), age range, and country in which the study was conducted.

Study characteristics

The characteristics of the 24 included studies can be found in Table 2.

-Insert Table 2 about here-

The final 24 articles identified for this review were published between 2002 and 2019, representing 20 original research studies. The studies describe the experiences of stigma in

people with a range of epilepsy diagnoses and seizure types, within a diverse range of settings. The countries of origin were the UK (n = 5), US (n = 4), Ireland (n = 1), Sweden (n = 3), Slovenia (n = 1), South Africa (n = 2), Nigeria (n = 1), Zambia (n = 1), Canada (n = 1), Australia (n = 2), Argentina (n = 1) and Iran (n = 1).

All the articles focused on the direct experiences of people with epilepsy. Data was collated via individual interviews (n = 18), focus groups, or a combination of focus groups and individual of both (n = 1). All the studies used a form of qualitative analysis to analyse the data guided by a range of methods including: content analysis (n = 8), thematic analysis (n = 6), phenomenological approach (n = 7), grounded theory (n = 2), and an ethnographic approach (n = 1).

Quality Appraisal

In order to assess the methodological and reporting quality of the included studies, the Critical Skills Appraisal Skills Programme (CASP) tool was administered.[47] The CASP tool has been developed for use by qualitative researchers in the field of health research, in order to appraise research across ten domains, on rigour, credibility and methodological findings that are considered vital in qualitative research. The 24 included papers were assessed by the lead author using the tool. According to guidance, each paper was scored 'yes', 'no', or 'can't tell' for the initial two screening questions. Further criteria were scored alongside a three-point rating system developed by Duggleby and colleagues.[48] Each paper was given a score between one and three, depending on whether the study provided a weak (1), moderate (2), or strong (3) description of the eight criteria. Four papers (17%) were appraised by an external rater, (trainee clinical psychologist) to ensure rigour. Inter-rater agreement was 88% (28/32 criteria). Where discrepancy was found, this was discussed and a final score agreed. A summary of the outcome of the quality rating procedure can be found in Table 3.

CASP scores ranged from 15 to 24 (potential range 8-24) indicating variability in the quality of reporting. Following Sandelowski,[49] studies were not excluded based on the appraisal score due to the lack of consensus of what makes 'good' qualitative research. For example, lower scores may be more indicative of reporting quality, influenced by journal word limit restrictions, rather than the actual research process.[50] For this reason, the quality appraisal was conducted in order to highlight the quality of reporting, rather than as a basis for inclusion or exclusion from the review.

-Insert Table 3 about here-

Data Analysis

Meta-synthesis is a method of systematically integrating the findings of qualitative research in an attempt to create new meaning.[51] For this review, the qualitative data included in the final 24 studies was analysed using Noblit and Hare's meta-ethnographic approach.[52] This approach was suited to the research question as it aims to retain the interpretative nature of qualitative studies rather than simply summarising the findings and attempts to identify new themes from the data.[53] Thus, an interpretive position was assumed throughout the synthesis.

Guidance for synthesizing qualitative literature[52] was followed alongside a worked example adapted for health research.[54] Recent guidance on the reporting of meta-ethnographies was also followed.[55] This seven-stage approach allows for the identification of higher order themes which provide an interpretative account of the synthesised studies. Following this process, the papers were read and re-read in order to become as familiar as possible with their content. In order to follow a systematic approach and in line with Atkins et al.,[50] studies were examined chronologically. The first iteration of themes was produced by identifying key themes and subthemes from the results section of each paper and summarising these using the original authors' language from the results and discussion

sections. A summary of the key findings from each of the included articles can be found in Appendix 1-C.

Next, studies were compared so that similarities and differences in themes and subthemes could be identified, determining how they were related. Through a process of reciprocal translation,[52] similar concepts were grouped and second-order constructs were formed. The same approach was used to develop the analysis, in which these translated constructs were grouped into new conceptual contexts to form final third-order constructs. Noblit and Hare's[52] method of generating 'lines of argument' was used to express the current author's interpretation of the synthesised results and, thereby, offer conceptual development beyond that of the individual studies.[56] To enhance validity, details of the analysis process are provided in Appendix 1-D.

Results

Five main themes were generated from the synthesis and are explored here.

Theme 1: Societal negative perceptions of epilepsy leading to discrimination and rejection

This theme illustrates how people with epilepsy described being viewed as different from what was culturally expected and experienced varying levels of discrimination from the public and those with whom they had relationships. This was often due to misconceptions about the nature of epilepsy but also due to the physical manifestations of seizures, which were not well understood.

Participants described a lack of public understanding regarding epilepsy, including causation, which predominantly resulted in being viewed negatively. In some cultures, misconceptions that epilepsy was caused by supernatural forces, such as witchcraft or demonic possession were described. Thus, affected individuals may be feared by others. Religious beliefs often inferred the development of epilepsy as a punishment for wrong-doing

and that the person with the condition had been "damned."[57(p.111)] Such perceptions indicated beliefs of blame towards the individual which maintained negative perceptions.[58]

Misunderstandings regarding the biological nature of epilepsy were also commonplace. In a study conducted in Slovenia, concerns regarding contagion existed as described by one participant: "She asked me if it is contagious and if she can get ill." [59(p.7)] Similarly, the physical manifestations of seizures might be misperceived as resulting from being under the influence of or withdrawing from illicit substances.[60] Public lack of knowledge regarding different types of epilepsy could also impact on others' perceptions: "I mean if you go down on the floor and shake people know what's going on… but when you're just talking a load of rubbish you know, they just think you're totally mad."[44(p.667)] Indeed, reports from a number of studies described perceptions regarding an association between epilepsy and mental illness.

Thus, epilepsy was referred to as a "taboo"[59(p.5)] and across cultures and contexts, those with the condition were not acceptable within society and thus marked lower in social value. Negative attitudes towards epilepsy were described across all studies as resulting in discrimination or rejection, both from the public and those closer to them. However, the extent and extremes of this varied, often dependent on the social and cultural perceptions regarding epilepsy in that setting.

For example, in settings in which supernatural causes for epilepsy dominated, so did the use of alternative treatments in order to 'cure' epilepsy, such as religious healing: "they believe [in Nigeria] it was a spiritual attack…they might do some cleansing." [61(p.454)] As such, people were vulnerable to extreme forms of assault: "I know of a woman with epilepsy who was beaten with extensive bodily injuries because she was thought to be possessed of an evil spirit."[62(p.45)] Other studies described experiences of physical and sexual assault,

rejection from the community and public humiliation and ridicule. Such negative societal views regarding people with epilepsy could result in complete rejection, even from family. Participants described how women with epilepsy living in urban settings in Africa were "sent back to the village"[63(p. 169)] which was seen as a poorer and less privileged society with which to belong.

Other misconceptions regarding epilepsy could result in enacted stigma, although less overt. For example, those who were viewed as being under the influence of drugs might be inappropriately treated: "They told her that they wouldn't call an ambulance for someone on drugs."[59(p.6)] When epilepsy was not viewed as a medical condition requiring treatment, this was often withheld. Even when epilepsy was viewed as having a biological cause, the perception that it might be hereditary could prevent others forming intimate relationships with someone with the condition, in case it was passed on to their children.[59]

Furthermore, participants also experienced discrimination due to misunderstandings regarding the hidden nature of the illness. For example, participants described experiences in which they were viewed as "lazy"[43(p.31)] perhaps for not working or not recovering quickly, because symptoms of the condition were invisible to others the majority of the time.

Interestingly, discriminatory behaviour was received not only from personal relationships and members of the public but also from healthcare professionals, who participants expected to understand better the causes and consequences of epilepsy. Accounts reported doctors not having the time to listen to their concerns, lacking empathy, or behaving as if they "don't care."[58(p.55)]

Theme 2: Internal attributions of blame lead to negative self-perception and shame

This theme describes how epilepsy stigma from society became internalised, resulting in negative self-perceptions. Participants described distress at identifying as someone with epilepsy and feelings of shame, often due to the impact on others.

Accounts indicated how cultural or societal beliefs about the nature of epilepsy influenced participants' own beliefs. Cultural perceptions about the nature of epilepsy, therefore, appeared to influence how individuals learned to identify themselves as someone with the condition and, as a result, negative associations with epilepsy could become internalised. For example, participants from African cultures, in which epilepsy was viewed as having supernatural causes, reported viewing themselves as "witches." [61(p. 455)] Similarly, where epilepsy was viewed as a curse for wrong doing, this resulted in participants blaming themselves for their condition

In contrast, in cultures in which a medical or neurological explanation for epilepsy was dominant, such as the US or Europe, participants described more readily accepting this explanation for their own condition. However, even in these studies, lack of clear public knowledge about epilepsy and, therefore, unclear individual cognitions about the nature of the condition, could still result in participants questioning whether they were to blame. For example, one participant in Sweden commented: "I think that I got the epilepsy due to the incident when my boyfriend died… He killed himself… I didn't follow him home the night it happened… I don't think I would have it if I had… and then I got my epilepsy 2 weeks later." [39(p.206)] Whilst another participant described: "It is an illness with spasms in the brain… the electrical currents [power] become too strong." [39(p.205)] Thus, accounts provided insight into how people with epilepsy appeared to make sense of their condition based on the dominant narratives within their society.

Therefore, cultural and individual perceptions about the nature of epilepsy, and negative associations led participants to feel different from what was expected within society. Moreover, in many studies, this sense of difference was described to be enduring, beyond the acute seizures themselves: "It's not the seizures, it's that effect of feeling different. It's not the physical reality, it's that psychological effect that just doesn't go away."[64(p. 283)] One study described a women's description of the word for her epilepsy "iyandiguqula" meaning 'epilepsy makes her a different person.'[46] This enduring sense of being different often led to negative self-perceptions including low self-worth: "I thought it was a miracle that there are people out there who would even talk to us"[59(p.5)] and disgust: "I felt like a 'mongo,' epilepsy is yucky, people that have it are dirty."[39(p.205)] Furthermore, this resulted in an expectation of societal rejection and thus participants conceded to this: "I'm a reject you know, basically, I'm one of nature's rejects."[44(p.669)]

Therefore, having a condition which was viewed negatively within society elicited a range of different negative cognitive and emotional experiences. This often appeared to be related to feelings of lack of control over the condition, due to its uncertain nature.

A common emotion which appeared associated with stigma, was shame. This appeared related to fears about the consequence of epilepsy becoming known to others due to its negative associations: "I don't want anyone to know that I have it… it is shameful… and I am afraid that it will come out that I have it."[39(p. 206)] This was demonstrated in the majority of the studies, but which was found to vary in severity across cultures and settings. Perhaps for this reason, in collectivist cultures, participants described greater distress and concern about the potential impact of their epilepsy on family members and community, than the personal emotional distress caused. This was demonstrated by African participants in a study conducted in the UK "The shame on me, it was too much, and the name on the family…

another family doesn't want anything to do with your family."[61(p.454)] Participants therefore demonstrated a sense of responsibility for others' responses to their epilepsy.

Furthermore, experiencing seizures in public led to feelings of guilt due to the perceived negative impact on witnesses. Participants described how seizures could be experienced as frightening to witness, particularly for children.[65] Participants also reported guilt at the potential to injure others during seizures.

Theme 3: Impact of stigma on everyday life and associated reliance on others

This third theme describes how having a stigmatised condition, such as epilepsy, affected all areas of daily life. Participants described the impact on fulfilling their expected societal roles and the possibilities for education and employment. Reliance on others and externally enforced decisions about their lives often resulted in individuals struggling to resist epilepsy taking over.

Participants described experiencing restrictions in many different areas of their lives as a result of epilepsy stigma, which appeared overwhelming and extensive, and meant that living a socially conventional lifestyle was more challenging. Such experiences appeared to lead to participants having a sense of a diminished and limited life: "When you are whole, you can do anything… When epilepsy is on your record, all doors close."[59(p.5)] In all of the studies, epilepsy was described as having a significant impact on individuals' ability to form and maintain relationships. For example, participants described epilepsy causing the ending of marital relationships or perceived epilepsy as a potential deterrent to marriage, while others already married feared their spouse would abandon them because of epilepsy. Therefore, participants described feeling thankful to their partner for being "still here."[65(p. 756)] In contrast, participants in a small number of studies described surprise at their partner's positive and protective response to their condition: "My partner says to me, you are special. You are not like all the rest… Yes it's a good match."[65(p. 756)] Such differences appeared to be

as a result of partners having a good understanding of epilepsy which protected against stigma.

The majority of female participants also described restrictions in their aspiration to become parents. Participants held beliefs that pregnancy could result in a worsening of their condition, that they may harm their developing baby or that their baby would also develop epilepsy, demonstrating their own misunderstanding regarding epilepsy.[39] This often appeared related to a lack of sufficient information, either as a result of limited access to healthcare or because professionals did not take the time to discuss this. In some cultures, the perceived inability to provide children within a relationship was described as being deeply shaming [63] and this perceived impossibility resulted in further feelings of grief and sadness: "It really hurts, knowing that I will never experience pregnancy, I will never have a child of my own."[39(p.206)] However, the impact of epilepsy on parenting in male participants was only clearly described in one study.[42]

Participants also described difficulties making and sustaining friendships, often due to the need to explain a condition which might not be well understood and fearing rejection. Indeed, participants described experiencing rejection or distancing from others after witnessing a seizure: "I even had friends that I've had a seizure, and now they're no longer my friends."[66(p.260)] Participants also described the discriminatory behaviour of others with whom they had formed relationships within wider society, such as friends from exercise settings,[67] religious groups or their places of residence[68] which resulted in decreased opportunities for social activities and interaction.

Participants across studies described experiencing significant restrictions in finding employment: "I didn't get a job because I have epilepsy and it was made very clear that that was the reason." [64(p. 283)] For some this was as a result of rejection from, or being unable to

access, school or disrupted education as a result of epilepsy in childhood which limited employment opportunities.[58] Additional limitations, such as not being able to drive were also described as impacting on employment.[65]

Having epilepsy could therefore have a negative impact on financial resources. In contexts in which finding work was crucial, lack of employment opportunities could have a devastating impact, including rejection from their partner or family, resulting in living in poverty and, thus, further exclusion.[62] In societies where this was available, participants described having to rely on support from benefit systems. However, this was often complicated by the hidden nature of epilepsy and lack of understanding which meant that participants often had to prove to be deserving of assistance: "I've had problems with a lot of resources refusing to help me, cause they're like you're relatively articulate so you're just making this up."[66(p.260)] However, not being able to work and having to rely on assistance could increase feelings of shame, due to concerns about not satisfactorily contributing to society. Participants therefore often appeared in a personal conflict which could be difficult to resolve.

Subsequent to the restrictions experienced by people with epilepsy, participant accounts described significant difficulties with loss of role, autonomy and independence. Participants described needing to rely heavily on others, for financial, practical and emotional support but which could result in a deep sense of disappointment and guilt about burdening those upon whom they depended.[40, 58, 60] Moreover, participants frequently reported feeling as though their decisions were externally enforced, be that by healthcare professionals, family or employers,[45] but which were sometimes believed to be incorrect as a result of others' "ignorance" regarding epilepsy.[65] Thus participants expressed a sense of powerlessness over their own lives.[59] Interestingly participants often described a sense of conflict between

appreciation of the support they were provided and finding the level of dependence restrictive and infantilising, particularly in cultures in which independence was encouraged.[42]

Theme 4: Attempts to manage stigma through concealment and avoidance.

This fourth theme illustrates how participants attempted to manage and cope with the stigma resulting from having epilepsy and the challenges this presented. Participants described differences in accepting or denying their diagnosis and behavioural strategies they put in place as a result of this. For some these strategies were protective while others recognised the potential to maintain the stigma associated with epilepsy, although inadvertently.

Participants described differences in their acceptance of their condition and adjustment to this. Several participant accounts described the denial of an epilepsy diagnosis. This often appeared related to participants' own perceptions regarding epilepsy. For example, one participant reported denial of epilepsy based on their seizure manifestations, including the perceived view that: "I don't have epilepsy because I do not foam from the mouth."[62(p.41)] While others described more explicitly their lack of knowledge being the reason for their denial. However, this also appeared to be a protective mechanism, which allowed participants to separate themselves from something which was perceived as negative: "unlike me, he has those… terrible seizures."[69(p.110)] Other participants described more active and severe behaviours in order to reject their condition, including relocating, in order to live "as though nothing has happened."[43(p.28)]

Even if participants accepted their condition, they often chose to keep this hidden from others in order to avoid stigma. Participants described great fear at their epilepsy being known to others due to fear of their reactions, often as a result of previous negative experiences of disclosure.[67] In some accounts, participants reported going to great lengths to keep their epilepsy concealed so to present themselves in a way which might be viewed as

'normal' within society: "I would get an aura [perceptual disturbance preceding a seizure], and I would get up and run to the bathroom, and I could hide it for years."[64(p.284)] Concealment appeared particularly prevalent when considering employment situations. Indeed, even in societies in which employment laws were in place to protect citizens, such as the US, participants described the direct experience of colleagues or employers witnessing a seizure which then resulted in dismissal.[64]

In contrast, other participants described being open about their epilepsy. For some this was on a need to know basis, for example regarding safety concerns and managing risk: "I tend to tell people, if they ask and if it's important."[44(p.671)] While for others this allowed a sense of liberation and the potential to be better understood by others. However, participants described the importance of being selective regarding who they informed about their epilepsy and the benefit of practising telling beforehand.[70] Moreover, levels of concealment were markedly dependent on context. Indeed, participants in studies conducted in societies where they might be more vulnerable to extreme levels of discrimination and abuse rarely described being open about their condition.

The majority of participants described fear of forced disclosure of their epilepsy, as a result of having a seizure in public and the potential for further discrimination. As a result, social withdrawal behaviours and self-isolation were common: "in the end I will end up going nowhere in case of having a seizure… the risk is that one becomes… well… kind of isolated." [40(p.1998)] While the majority of accounts described this as protective, some identified how such behaviour resulted in further limitations on life and the ability to form relationships. However, this was also described as being the lesser of two evils: "it is easier to stay at home and be lonely than need to discuss [epilepsy] and be judged by society."[43(p.29)]

Interestingly, however, participants identified how their own lack of disclosure might contribute to the lack of knowledge in others: "I don't speak about it so maybe that's the problem."[68(p.89)] Therefore, it was felt that concealment may inadvertently have maintained stigma in epilepsy.[69] This led to feelings of ambivalence in some participants. However, in many contexts the risk of exposure continued to outweigh this responsibility and was therefore not sufficient to change disclosure behaviour.

Theme 5: Support from others is beneficial but dependent on own and others' understandings of epilepsy

Contrary to the many difficulties described by participants in adjusting to the challenges presented by epilepsy and stigma, this final theme describes the strategies and resources adopted by participants. Participants described the need for support, mostly from family but also wider society, which was improved by better knowledge about epilepsy. Participants therefore described the need for better education and more accurate media representation regarding epilepsy.

Participants described relying on others for practical and emotional support. Perhaps due to the dependency on others previously outlined, participants described having a supportive family as critical to managing epilepsy and stigma. Indeed, supportive others could improve accessing healthcare which might otherwise be inaccessible, due to practical restrictions, or feeling unable to navigate this independently. Furthermore, participants described the benefit of family support to manage the emotional impact of stigma and practical limitations of the condition.[71]

Therefore, participants in many of the studies described the ongoing need for education about epilepsy both for themselves and others, as it was believed that: "a lot of stuff people don't understand, scares them."[72(p.110)] Participants, therefore, described how

increased awareness about the heterogenous nature of the condition and potential invisibility of epilepsy had the potential to reduce negative misperceptions and increase empathy.[68]

Individual coping strategies were also reported. One participant described restructuring negative cognitions to view the self as a survivor.[43] Others described the importance of improved self-care or resilience.[68] However, these were often dependent on social circumstances and appeared predominantly in the descriptions of those who also reported sufficient support from others and who thus perceived themselves as having a better quality of life.

Only a small number of participants described the benefits of professional emotional support, perhaps due to the focus of interview schedules, but likely related to frequent reports of inadequate healthcare. Subsequently, participants described the need for improved knowledge of the wider socioeconomic impact of epilepsy in healthcare professionals in an attempt to improve empathy and care.[69]

The benefit of support groups in which others shared the same knowledge and experiences of epilepsy and stigma were discussed, describing a unique opportunity for care. As many participants experienced social isolation, support groups provided an opportunity for social interaction and a means of expressing negative feelings: “So we need a place where people can go to open up. Some kind of group or something.”[66(p. 261)] However, these were not available to participants in the majority of studies and, therefore, mentioned rarely across accounts.

Therefore, participants in a number of studies felt that it was the collective responsibility of the wider society to educate and correct misinformation about epilepsy. One participant described ongoing epilepsy stigma as a consequence of what is “seen on TV”

[72(p.11)] The authors in this study therefore discussed the potential for misrepresentations of epilepsy in the media maintaining stigma.

Furthermore, participants in a number of studies described feeling let down by members of their community. Descriptions regarding the responsibility of institutions, such as churches and schools, taking more responsibility for educating society about epilepsy were commonplace. This was particularly evident in collectivist cultures, or settings in which particular institutions were significantly influential on the views of the community. Interestingly, even when misperceptions about the causes of epilepsy remained, a positive attitude towards epilepsy in a particular group or setting could be protective.

Discussion

The aim of this review was to understand and synthesise the experiences of stigma in adults with epilepsy across cultures and contexts. The meta-ethnographic method of synthesis has allowed for individual perspectives of epilepsy, across a variety of contexts, to be incorporated into the review, from which key experiences have been identified. Themes highlighted the adverse experiences of people with epilepsy as result of stigma and discrimination. Although this has been evidenced in previous studies, this review offers a conceptualisation of the individual experiences of epilepsy-related stigma, dependent on sociocultural representations of epilepsy. Misconceptions regarding epilepsy were readily internalised which led to negative self-perceptions and widespread implications for participants' lives. Thus, participants demonstrated a process of psychological and practical adaptation to overcome these challenges. Although participants described a range of strategies, support from others appeared crucial. Thus, the need for improved societal understandings regarding epilepsy was highlighted.

Misconceptions about epilepsy were common but influenced by the sociocultural context. Negative representations of epilepsy were associated with varying degrees of discrimination. Extreme acts arising from stigma were more common in societies in which supernatural explanations dominated, such as parts of Africa, whereas more subtle experiences were described by participants in studies conducted in societies in which medical explanations dominated, such as the US and Europe. It has previously been proposed that experiences of felt stigma might be of greater concern for people with epilepsy in the developed world (due to improved seizure control) compared to experiences of enacted stigma greater in the developing world.[3] While this review provides some evidence for this distinction, qualitative exploration of these experiences highlighted that people with epilepsy across cultures experienced both felt and enacted stigma. Such a broad distinction could therefore result in more subtle forms of stigma being ignored. Instead, this review highlights the need for consideration of sociocultural factors to understand fully individual experiences of stigma.

Furthermore, these culturally informed misconceptions were also internalised which resulted in significant negative self-perceptions. It has been suggested that felt stigma, or fear of enacted stigma, may be more of a burden and have a greater influence on the lives of people with epilepsy than that of enacted stigma itself.[73] Indeed, this review highlighted the extensive perceived implications of felt and anticipated stigma on participants' lives and attempts to overcome this.

Moreover, participants described restrictions in many aspects of daily life as a result of stigma, dependent on sociocultural context. Participants described significant restrictions which were perceived as externally enforced, including the impact of stigma on forming and maintaining relationships, the ability to marry and start a family, possibilities for social activity, education and employment. Social models of disability are, therefore, also likely to

be of relevance. Indeed, it is proposed that perspectives from both disability studies and clinical psychology can be usefully combined to understand distress in those who experience disability.[74]

Social models of disability have been used to explain the experiences of people with mental health difficulties[75], intellectual impairment[76] and other neurological conditions.[77] While earlier social models of disability were criticised for not taking into sufficient account individual experiences of disability and the psychological and emotional processes involved,[78] in a reformulation of such, Thomas introduced the concept of psycho-emotional disablism.[78] This social relational definition of disablism identifies two dimensions that can disable people: environments that may exclude what people can 'do' (such as the lack of health care services or inappropriate workplaces described by participant accounts here) and social interactions that can impact on psychological wellbeing and what people can 'be'.[79] Thus, it can be defined as: "a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being."[80(p.73)]

Consistent with this concept, the majority of barriers described by participants appeared socially enforced; negative social interactions, such as avoidance and rejection from others, resulting in negative self-perceptions and shame. As such, participants described reduced social interaction and attempts to conceal epilepsy, often through lack of disclosure. Disclosure behaviour in adjustment to epilepsy has previously been described.[81] Here, the authors described three modes of disclosure: 'pragmatic' in which people advise those who need to know; 'secret' in which epilepsy is concealed; and 'quasi-liberated' in which the condition is disclosed in order to educate others about their prejudices. However, across studies, significant cultural differences were evident in disclosure behaviour. Further, participants in some studies identified the potential for lack of disclosure of epilepsy as

having the potential to maintain stigma as a result of continued lack of education about the heterogeneity of epilepsy. However, such views were only relevant to societies in which disclosure may be safe due to legal protections. For participants who resided in cultures in which disclosure may increase risk of harm through vulnerability to abuse, concealment appeared adaptive.

In social relational definitions of disablism, such concealment behaviours are described as 'passing'[82] and used in attempts to appear 'normal'. However, passing can have negative psychological consequences, including significant physical and emotional efforts, and the risk of exposure. Indeed, participants described extreme attempts to hide their epilepsy, for example relocating. Furthermore, participants described the fear of epilepsy becoming discovered.

A second form of psycho-emotional disablism, indirect psycho-emotional disablism, has been described.[82] This relates to the psycho-emotional impact of physical or structural barriers. In this review there was also significant evidence of indirect psycho-emotional disablism. For example, participants who did not have accurate information regarding epilepsy and pregnancy perceived themselves as unable to have children. Furthermore, participants described inability to work or receive income support benefits due to misunderstandings regarding epilepsy.

Participants in a number of the studies described the shame they felt at the impact of their epilepsy on others, particularly their family. This is consistent with the concept of 'courtesy stigma'. Goffman originally argued that individuals can be subject to stigma through their association with a stigmatised person as opposed to an attribute of their own. Courtesy stigma has been shown in other health conditions such as HIV/AIDS[83] and may explain the rejection of people with epilepsy from close others. This is an important

consideration for improving the negative impact of stigma as seeking support was described as one of the main coping strategies.

Participants described a range of negative cognitive and emotional experiences resulting from stigma and, therefore, the findings are consistent with quantitative studies that suggest that epilepsy stigma is correlated with poorer psychosocial wellbeing.[9] Recommendations have been made for the need for psychotherapeutic interventions that might address the spectrum of difficulties experienced by people with epilepsy.[84] The findings here suggest that such interventions may be helpful for aspects of felt stigma to reappraise cognitions and enhance self-directed emotions and self-care. However, few participants described access to such support. Indeed, while there is a dearth of literature describing the psychosocial burden of epilepsy, few published studies have described psychological interventions for the impact of epilepsy,[85] thus limiting our understanding of the outcomes of such. Recent recommendations for the psychological treatment of people with epilepsy have been provided.[86] However, while interventions to counter the psychosocial impact of epilepsy and stigma were strongly encouraged, recommendations focused solely on individual-based approaches, such as interventions aimed at improving social and communication skills or individual psycho-education regarding epilepsy. The findings in this review, however, suggest that such interventions may not fully meet the needs of people with epilepsy due to the impact of sociocultural factors. Furthermore, such an approach may in fact inadvertently maintain stigma by focusing the blame on the individual. Instead, this review highlights the need for ongoing educational programmes for improving awareness of epilepsy across the world. Future research should, therefore, continue to focus on distributing research and education to the wider population in order to combat epilepsy misconceptions in the future. Indeed, if negative perceptions or misconceptions about epilepsy reduced, people with epilepsy would likely experience fewer negative social

interactions and less psycho-emotional disablism. However, it is recognised that due to the deep-seated nature of stigma, change in perceptions is unlikely to be easy.[87] However, lessons could be learnt from interventions aimed at reducing stigma in other conditions, such as HIV/AIDS.[88] For example, interventions may need to consider target audience (for example family members, healthcare professionals) and outcome (for example stigma-related knowledge, attitudes, and intended behaviour).[89]

A number of participants also described the benefit of support groups in order to provide a space to be open about their condition and as a means of securing safe social interaction. Many epilepsy charities in the developed world, offer such opportunities. However, such groups may not be available in all societies. Programmes which aim to provide opportunities for safe discussion about epilepsy in different sociocultural contexts would, therefore, be of benefit for future consideration.

A qualitative meta-synthesis has allowed for the voices of a larger number of participants to be considered in understanding the experiences of epilepsy stigma across cultures and the meta-ethnographic approach has allowed for individual participants' experiences to be preserved. However, in terms of limitations, synthesis relies not only on the language of the participants but the interpretations of the authors of the individual studies. The results discussed here are, therefore, likely to be affected by the views of the authors of the original research. The variability in the quality of the papers that were included in the synthesis has further potential impact for the findings presented here. The CASP tool[90] was utilised only to describe the reporting quality of the included studies. It is of note that few authors provided information regarding their own role and influence on the research process and therefore failed to demonstrate reflexivity, making it is difficult to judge the integrity of the findings.[91] Further, many of the studies were limited in the transparency of their analysis, which is essential in qualitative research.[92]

The variation in samples of people with epilepsy may be considered both a strength and limitation to this review. Within studies, different experiences of stigma were discussed according to seizure type. Therefore, the experiences of participants who experience tonic-clonic seizures may be different from those of others. However, incorporating studies which contained the experiences of participants with different aetiologies has also provided insights into these differences. Similarly, studies were conducted at different time points ranging from 2002 to 2019 and their findings may have therefore been influenced by socioeconomic changes. For example, the World Health Organization (WHO) Global Campaign against Epilepsy "Out of the Shadows"[30] was ongoing throughout this time which could have involved education projects in the study settings.

Studies conducted in a large number of different countries is a strength of this review. However, due to interviews being conducted in languages other than English, meaning may have been interpreted differently during the process of translation. Therefore, the meta-synthesis process relied on the quality of translations produced by the authors of the studies which cannot be determined.

The revised literature search identified an increase in qualitative studies exploring epilepsy stigma conducted in recent years. This is encouraging as it demonstrates an increase in research interest in this area of study. It is recognised that earlier investigations into epilepsy stigma were confined to a relatively small number of researchers,[93] which may have limited the scope of our understanding regarding the topic as it likely that existing models relied heavily on the experiences and assumptions of these authors. Continued empirical investigations in this area will continue to add to the existing knowledge base, providing broader insights into the relationships between epilepsy and stigma and thus, further informing treatment approaches to such.

In conclusion, the current meta-synthesis has described the experiences of stigma in adults with epilepsy and highlighted some of the key similarities and differences in these experiences across sociocultural contexts. Culturally informed misconceptions of epilepsy were readily internalised which resulted in emotional challenges for participants and had far-reaching implications on participants' lives. While individual strategies to cope with the impact were utilised, opportunities for educational programmes to inform about the neurological nature of epilepsy continue to have relevance.

References

1. Fisher RS, Acevedo C, Arzimanoglou A, et al. ILAE Official Report: A practical clinical definition of epilepsy. Epilepsia. 2014;55(4):475-82.
2. Kerr MP. The impact of epilepsy on patients' lives. Acta Neurol Scand. 2012; 126(194):1-9.
3. Baker GA. The psychosocial burden of epilepsy. Epilepsia. 2002;43(6):26-30.
4. Quintas R, Raggi A, Giovannetti AM, et al. Psychosocial difficulties in people with epilepsy: a systematic review of literature from 2005 until 2010. Epilepsy Behav. 2012;25(1):60-7.
5. Jacoby A, Baker GA, Steen N, et al. The clinical course of epilepsy and its psychosocial correlates: findings from a UK community study. Epilepsia. 1996;37(2):148-61.
6. Krumholz A. Driving Issues in Epilepsy: Past, Present, and Future. Epilepsy Curr. 2009;9(2):31-5.
7. Elwes RD, Marshall J, Beattie A, et al. Epilepsy and employment. A community based survey in an area of high unemployment. J Neurol Neurosurg Ps. 1991;54(3):200-3.
8. Jacoby A. Stigma, epilepsy, and quality of life. Epilepsy Behav. 2002;3(6):10-20.

9. Jacoby A. Felt versus enacted stigma: A concept revisited: Evidence from a study of people with epilepsy in remission. Soc Sci Med. 1994;38(2):269-74.
10. Westbrook LE, Bauman LJ, Shinnar S. Applying stigma theory to epilepsy: a test of a conceptual model. J Pediatr Psychol. 1992;17(5):633-49.
11. Goffman E. Stigma; notes on the management of spoiled identity: Englewood Cliffs, N.J. : Prentice-Hall, 1963.
12. Link BG, Phelan JC. Conceptualizing Stigma. Annu Rev Sociol. 2001;27:363-85.
13. Hatzenbuehler ML, Phelan JC, Link BG. Stigma as a fundamental cause of population health inequalities. Am J Public Health. 2013;103(5):813-21.
14. Earnshaw VA, Chaudoir SR. From conceptualizing to measuring HIV stigma: a review of HIV stigma mechanism measures. AIDS and behavior. 2009;13(6):1160-77.
15. Link BG, Cullen FT, Struening EL, et al. A modified labeling theory approach to mental disorders: An empirical assessment. Am Sociol Rev. 1989;54(3):400-23.
16. Quinn DM, Chaudoir SR. Living with a concealable stigmatized identity: the impact of anticipated stigma, centrality, salience, and cultural stigma on psychological distress and health. Journal of personality and social psychology. 2009;97(4):634-51.
17. Earnshaw VA, Quinn DM. The impact of stigma in healthcare on people living with chronic illnesses. Journal of health psychology. 2012;17(2):157-68.
18. Jacoby A, Austin JK. Social stigma for adults and children with epilepsy. Epilepsia. 2007;48:6-9.
19. Herrmann LK, Welter E, Berg AT, et al. Epilepsy misconceptions and stigma reduction: current status in Western countries. Epilepsy Behav. 2016;60:165-73.
20. Kim HD, Kang H-C, Lee SA, et al. Changing name of epilepsy in Korea; cerebroelectric disorder (noi-jeon-jeung, 뇌전증,): my epilepsy story. Epilepsia. 2014;55(3):384-6.

21. Scambler G, Hopkins A. Generating a model of epileptic stigma: The role of qualitative analysis. Soc Sci Med. 1990;30(11):1187-94.
22. Muhlbauer S. Experience of stigma by families with mentally ill members. J Am Psychiatr Nurses Assoc. 2002;8(3):76-83.
23. de Boer HM, Mula M, Sander JW. The global burden and stigma of epilepsy. Epilepsy Behav 2008;12(4):540-6.
24. Baker GA, Brooks J, Buck D, et al. The stigma of epilepsy: a European perspective. Epilepsia. 2000;41(1):98-104.
25. Baker GA, Jacoby A, Buck D, et al. Quality of life of people with epilepsy: a European study. Epilepsia. 1997;38(3):353-62.
26. Alaqeel A, Alebdi F, Sabbagh AJ. Epilepsy: what do health-care professionals in Riyadh know? Epilepsy Behav. 2013;29(1):234-7.
27. Ekenze O, Ndukuba A. Perception of epilepsy among public workers: perspectives from a developing country. Epilepsy Behav. 2013;26(1):87-90.
28. Kerson TS, Kerson LA. Truly Enthralling: Epileptiform Events In Film and On Television—Why They Persist and What We Can Do About Them. Social Work in Health Care. 2008;47(3):320-37.
29. McNeil K, Brna PM, Gordon KE. Epilepsy in the Twitter era: a need to re-tweet the way we think about seizures. Epilepsy Behav. 2012;23(2):127-30.
30. De Boer HM. “Out of the Shadows”: A Global Campaign Against Epilepsy. Epilepsia. 2002;43(6):7-8.
31. Kaddumukasa M, Kaddumukasa MN, Buwembo W, et al. Epilepsy misconceptions and stigma reduction interventions in sub-Saharan Africa, a systematic review. Epilepsy & behav. 2018;85:21-7.

32. MacLeod JS, Austin JK. Stigma in the lives of adolescents with epilepsy: a review of the literature. Epilepsy Behav. 2003;4(2):112-7.

33. Chong L, Jamieson NJ, Gill D, et al. Children's experiences of epilepsy: a systematic review of qualitative studies. Pediatrics. 2016;138:3.

34. Harden J, Black R, Chin RF. Families' experiences of living with pediatric epilepsy: a qualitative systematic review. Epilepsy Behav. 2016;60:225-37.

35. Tanywe A, Matchawe C, Fernandez R. The experiences of people living with epilepsy in developing countries: a systematic review of qualitative evidence. JBI Database Syst Rev Implement Rep. 2016;14(5):136-92.

36. Baker D, Eccles FJR, Caswell HL. Correlates of stigma in adults with epilepsy: A systematic review of quantitative studies. Epilepsy Behav. 2018;83:67-80.

37. Aydemir N, Trung DV, Snape D, et al. Multiple impacts of epilepsy and contributing factors: findings from an ethnographic study in Vietnam. Epilepsy & behav. 2009;16(3):512-20.

38. Kilinc S, Campbell C, Guy A, et al. Epilepsy, identity, and the experience of the body. Epilepsy Behav. 2018;89:42-7.

39. Räty LKA, Larsson G, Starrin B, et al. Epilepsy patients' conceptions of epilepsy as a phenomenon. J Neurosci Nurs. 2009;41(4):201-10.

40. Räty LK, Wilde-Larsson BM. Patients' perceptions of living with epilepsy: A phenomenographic study. J Clin Nurs. 2011;20(13-14):1993-2002.

41. Keikelame MJ, Swartz L. "The others look at you as if you are a grave": a qualitative study of subjective experiences of patients with epilepsy regarding their treatment and care in Cape Town, South Africa. BMC Int Health Human Rights. 2016;16:9.

42. Raffaele M. A Qualitative Study Exploring Family Life in Men Following Neurosurgery for Adult Onset Epileptic Seizures. Austr J Rehabil Couns. 2018;24:55-66.

43. Raffaele M, Mpofu E, Smith-Merry J, et al. Men with Adult Onset Epileptic Seizures: Their Coping Strategies and Sense of Subjective Wellbeing following Elective Neurosurgery. Austr J Rehabil Couns. 2017;23:1-18.

44. Kilinc S, Campbell C. "It shouldn't be something that's evil, it should be talked about": a phenomenological approach to epilepsy and stigma. Seizure. 2009;18(10):665-71.

45. Kilinc S, van Wersch A, Campbell C, et al. The experience of living with adult-onset epilepsy. Epilepsy Behav. 2017;73:189-96.

46. Keikelame MJ, Swartz L. "I wonder if I did not mess up....": Shame and resistance among women with epilepsy in Cape Town, South Africa. Seizure. 2018;61:50-6.

47. Tracy J, Robins R. Putting the Self into Self-conscious Emotions: A Theoretical Model. Psychological Inquiry. Psychol Inq. 2004;15:103-25.

48. Duggleby W, Holtslander L, Kylma J, et al. Metasynthesis of the hope experience of family caregivers of persons with chronic illness. Qual Health Res. 2010;20(2):148-58.

49. Sandelowski M, Docherty S, Emden C. Focus on qualitative methods Qualitative metasynthesis: issues and techniques. Res Nurs and Health. 1997;20:365-72.

50. Atkins S, Lewin S, Smith H, et al. Conducting a meta-ethnography of qualitative literature: lessons learnt. BMC Med Res Methodol. 2008;8(1):21.

51. Harden A, Thomas J. Methodological issues in combining diverse study types in systematic reviews. Int J. Soc Res Methodol. 2005;8(3):257-71.

52. Noblit GW, Hare RD. Meta-ethnography: Synthesizing qualitative studies: sage; 1988.

53. Campbell R, Pound P, Pope C, et al. Evaluating meta-ethnography: a synthesis of qualitative research on lay experiences of diabetes and diabetes care. Soc Sci Med. 2003;56(4):671-84.

54. Britten N, Campbell R, Pope C, et al. Using meta ethnography to synthesise qualitative research: a worked example. J. Health Serv Res policy. 2002;7(4):209-15.

55. France EF, Cunningham M, Ring N, et al. Improving reporting of meta-ethnography: The eMERGe reporting guidance. Psycho-oncology. 2019;28(3):447-58.

56. Reid B, Sinclair M, Barr O, et al. A meta-synthesis of pregnant women's decision-making processes with regard to antenatal screening for Down syndrome. Soc Sci Med. 2009;69(11):1561-73.

57. Molavi P, Sadeghieh Ahari S, Fattahzadeh-Ardalani G, et al. The experiences of Iranian patients with epilepsy from their disease: A content analysis. Epilepsy Behav 2019;96:109-13.

58. Sarudiansky M, Korman GP, Scevola L, et al. A life with seizures: Argentine patients' perspectives about the impact of drug-resistant epilepsy on their lives. Seizure. 2018;63:52-61.

59. Mlinar S, Petek D, Cotic Z, et al. Persons with Epilepsy: Between Social Inclusion and Marginalisation. Beh Neurol. 2016;2016:2018509.

60. Crooks RE, Bell M, Patten SB, et al. Mind the gap: Exploring information gaps for the development of an online resource hub for epilepsy and depression. Epilepsy Behav. 2017;70(Pt A):18-23.

61. Sonecha S, Noble AJ, Morgan M, et al. Perceptions and experiences of epilepsy among patients from black ethnic groups in South London. Prim Health Care Res 2015;16(5):450-60.

62. Komolafe MA, Sunmonu TA, Fabusiwa F, et al. Women's perspectives on epilepsy and its sociocultural impact in South Western Nigeria. AJNS. 2011;30:2.

63. Birbeck GL, Chomba E, Atadzhanov M, et al. Women's experiences living with epilepsy in Zambia. Am J Trop Med Hyg. 2008;79(2):168-72.

64. Bishop M. Barriers to employment among people with epilepsy: Report of a focus group. J Vocat Rehabil. 2002;17(4):281-6.

65. Gauffin H, Flensner G, Landtblom A-M. Living with epilepsy accompanied by cognitive difficulties: Young adults' experiences. Epilepsy Behav. 2011;22(4):750-8.

66. Chung K, Liu Y, Ivey SL, et al. Quality of life in epilepsy (QOLIE): insights about epilepsy and support groups from people with epilepsy (San Francisco Bay Area, USA). Epilepsy Behav. 2012;24(2):256-63.

67. Collard SS, Ellis-Hill C. 'I'd rather you didn't come': The impact of stigma on exercising with epilepsy. Journal Health Psych. 2019;24(10):1345-55.

68. Yennadiou H, Wolverson E. The experience of epilepsy in later life: A qualitative exploration of illness representations. Epilepsy Behav. 2017;70:87-93.

69. Paschal AM, Ablah E, Wetta-Hall R, et al. Stigma and safe havens: a medical sociological perspective on African-American female epilepsy patients. Epilepsy Behav. 2005;7(1):106-15.

70. Pembroke S, Higgins A, Pender N, et al. Becoming comfortable with "my" epilepsy: Strategies that patients use in the journey from diagnosis to acceptance and disclosure. Epilepsy Behav. 2017;70:217-23.

71. Jacoby A, Ring A, Whitehead M, et al. Exploring loss and replacement of loss for understanding the impacts of epilepsy onset: a qualitative investigation. Epilepsy Behav. 2014;33:59-68.

72. Sleeth C, Drake K, Labiner DM, et al. Felt and enacted stigma in elderly persons with epilepsy: A qualitative approach. Epilepsy Behav. 2016;55:108-12.

73. Scambler G, Hopkins A. Being epileptic: coming to terms with stigma. Soc Health Ill. 1986;8(1):26-43.

74. Simpson J, Thomas CJD.Clinical psychology and disability studies: Bridging the disciplinary divide on mental health and disability. Rehabilitation.2015;37(14):1299-304.

75. Beresford PJMH. Thinking about'mental health': Towards a social model. 2002;11(6):581-4.

76. Goodley DJD, Society. 'Learning difficulties', the social model of disability and impairment: challenging epistemologies. 2001;16(2):207-31.

77. Simpson J, McMillan H, Reeve DJPsD. Reformulating psychological difficulties in people with Parkinson’s disease: the potential of a social relational approach to disablism. Parkinson's Disease. 2013;.

78. Thomas C. Female forms: Experiencing and understanding disability: McGraw-Hill Education (UK); 1999.

79. Reeve DJD, introductions pC, reflections. Towards a psychology of disability: The emotional effects of living in a disabling society. 2006:94-107.

80. Thomas C. Sociologies of disability and illness: Contested ideas in disability studies and medical sociology: Macmillan International Higher Education; 2007.

81. Schneider JW, Conrad P. Medical and sociological typologies: The case of epilepsy. Soc Sci Med Part A. 1981;15(3):211-9.

82. Reeve DJRhods. Psycho-emotional disablism. Routledge handbook of disability studies. 2012:78-92.

83. Herek GM, Mitnick L, Burris S, et al. AIDS and Stigma: A Conceptual Framework and Research Agenda Final Report from a Research Workshop Sponsored by the National Institute of Mental Health. 1998.
84. Kerr MP, Mensah S, Besag F, et al. International consensus clinical practice statements for the treatment of neuropsychiatric conditions associated with epilepsy. Epilepsia. 2011;52(11):2133-8.
85. Mittan RJ. Psychosocial treatment programs in epilepsy: a review. Epilepsy & Behavior. 2009;16(3):371-80.
86. Michaelis R, Tang V, Wagner JL, et al. Psychological treatments for people with epilepsy. The Cochrane database of systematic reviews. 2017;10:10
87. Fernandes PT, Snape DA, Beran RG, et al. Epilepsy stigma: what do we know and where next? Epilepsy Behav. 2011;22(1):55-62.
88. Brown L, Macintyre K, Trujillo LJAe, et al. Interventions to reduce HIV/AIDS stigma: what have we learned? AIDS Edu Preve. 2003;15(1):49-69.
89. Gronholm PC, Henderson C, Deb T, et al. Interventions to reduce discrimination and stigma: the state of the art. Soc. Psychiatry Psychiatr. Epidemiol. 2017;52(3):249-58.
90. Jacoby A, Snape D, Baker GA. Epilepsy and social identity: the stigma of a chronic neurological disorder. Lancet Neurol. 2005;4(3):171-8.
91. Yardley LJ. Demonstrating validity in qualitative psychology2008. 235-51 p.
92. Yardley L. Dilemmas in qualitative research. Psychol Health. 2000;15:215-28.
93. Jacoby AJE, Behavior. Thirty years of psychosocial research in epilepsy: Personal reflections of a social scientist. Epilepsy Behav. 2015;44:245-9.

Table 1: Inclusion/Exclusion Criteria

Studies eligible for inclusion in the review	a.	Studies which explored experiences of stigma from the perspective of adults with epilepsy.
	b.	Studies which included people who had received a diagnosis of any form of epilepsy (but which had an onset at any time point).
	c.	Studies which were based on a population of adult participants, 18 years or older at the time of the study (but whom may have received a diagnosis in childhood).
	d.	Studies which used a qualitative content-based (as opposed to discourse-based) approach to data collection (using face to face methods such as interviews or focus groups).
	e.	Studies in which the researcher(s) obtained, analysed and presented data from people with epilepsy separately from any other samples included in the research paper i.e. family members of people with epilepsy, controls, individuals people with predominantly other health conditions.
	f.	Published in the English language.
	g.	Studies which presented original research.
	h.	Published in a peer-reviewed academic journal.
Studies excluded from the review	a.	Studies in which the research question was focused on other experiences of epilepsy such that the concept of stigma was not explored sufficiently to be presented as a theme for discussion in the title or abstract of the article.
	b.	Mixed-design studies in which the qualitative data were not separately analysed and presented.
	c.	Publications which did not support themes with the inclusion of direct quotations from people with epilepsy.
	d.	Studies which did not report a named method of qualitative data analysis.
	e.	Studies in which the perspectives of other populations were included but which the experiences of participants with epilepsy could not be easily determined.

Table 2: Characteristics of the included studies

Authors	Year	Title	Research question/Aim	Methodology	Participants/	Setting
Bishop	2002	Barriers to employment among people with epilepsy: Report of a focus group	To explore the employment experiences and barriers to employment faced by adults with epilepsy.	Single focus group; Form of thematic analysis	Sample size: n= 14; Sample: Six males and eight female adults with epilepsy; Age: from 20 to 50 years	Setting: Two metropolitan areas (Ohio and Kentucky), USA
Paschal et al.	2005	Stigma and safe havens: a medical sociological perspective on African-American female epilepsy patients	To explore the attitudes and behaviours of a minority group, African-American women with epilepsy	Individual unstructured ethnographic interviews; unspecified form of thematic analysis	Sample size: n=10; Sample: African-American women with epilepsy; Age: 29-58 years	Setting: Specialist and primary care centres, Midwest USA (Wichita)
Birbeck et al.	2008	Women's experiences living with epilepsy in Zambia	To identify relevant areas of the lives of people with epilepsy that might be relevant to consider in future quantitative studies.	Focus groups of women with epilepsy; Unspecified form of content analysis, main themes identified	Sample size: Six groups of 8-15 participants; Sample: Women with epilepsy; Age: Adult women	Setting: Zambia, urban clinic and rural (Tonga) region
Kilinc & Campbell	2009	It shouldn't be something that's evil, it should be talked about: a phenomenological approach to epilepsy and stigma	To explore the experience of stigma for adults with epilepsy using a phenomelogical approach	Two individual semi-structured interviews undertaken six to twelve months apart; Analysed using phenomenological analysis	Sample size: n= 52 ; Sample: Adults with epilepsy ; Age: 18+	Setting: Community setting in UK
Räty et al.	2009	Epilepsy patients' conceptions of epilepsy as a phenomenon	To explore the concept of epilepsy and the emotions related to this in people with epilepsy	Individual interviews; analysed by phenomenographic method	Sample size: n=19; Sample: People with epilepsy (7 men, 12 women); Age: 20-65	Setting: Sweden, recruited from clinics (county and private)
Räty & Wilde-Larsson	2011	Patients' perceptions of living with epilepsy: A	To describe how patients with epilepsy	Individual interviews; analysed by the	Sample size: n=19; Sample: People with epilepsy (7	Setting: Sweden, recruited from

		phenomenographic study	perceive living with epilepsy	phenomenographic method	men, 12 women); Age: 20-65	clinics (county and private)
Gauffin et al.	2011	Living with epilepsy accompanied by cognitive difficulties: Young adults' experiences	To explore young adult's experiences of living with epilepsy and subjective cognitive decline	Focus groups (two made up of women with epilepsy and two of men); Analysed using Content analysis	Sample size: n=14; Sample: Young adults (7 males and 7 females) with epilepsy; Age: 18-35	Setting: Eastern Sweden
Komolafe et al.	2011	Women's perspectives on epilepsy and its sociocultural impact in South Western Nigeria	To explore the sociocultural aspects of epilepsy for women in Southwest Nigeria who already face gender based marginalisation	Six focus groups: three in urban areas, three in rural areas; Analysed using content analysis	Sample size: Six focus groups of 8-15 women; Sample: Women with epilepsy in Southwest Nigeria (mostly of the Yoruba population); Age: Adult women	Setting: rural and urban setting in Southwest Nigeria
Chung et al.	2012	Quality of life in epilepsy (QOLIE): insights about epilepsy and support groups from people with epilepsy (San Francisco Bay Area, USA)	To investigate the perceived quality of life in people with epilepsy who attend support groups compared to those who do not.	Six focus groups: three including people with epilepsy who attend support groups and three who do not; Content and interpretative qualitative analysis by the constant comparative method	Sample size: n= 36 (18 who attended support groups, 18 who did not); Sample: Male and female adults with epilepsy; Age: 24-65+	Setting: Community based, San Francisco Bay, USA
Jacoby et al.	2014	Exploring loss and replacement of loss for understanding the impacts of epilepsy onset: A qualitative investigation.	To gain an in-depth understanding of the lived experience of loss for people with epilepsy and to explore the relationships between different influences mediating loss and contributing to overall quality of life.	Individual interviews; analysed using Constant Comparative method	Sample size: n=67; Sample: Adults with epilepsy; Age: 24-65 years	Setting: Community setting in UK
Sonecha et al.	2015	Perceptions and experiences of epilepsy among patients from	To explore perceptions and experiences of epilepsy among black	Individual semi-structured interviews; analysed thematically	Sample size: n = 11; Sample: Black African and Caribbean people with	Setting: UK Recruited via South London hospitals

		black ethnic groups in South London	African and Caribbean people in South London		epilepsy (6 male, 7 female); Age: 22-79	
Sleeth et al.	2016	Felt and enacted stigma in elderly persons with epilepsy: A qualitative approach	To qualitatively assess the effects of stigma upon the quality of life of elderly persons with epilepsy	Individual semi-structured interviews; analysed by non-specified form of thematic analysis	Sample size: n=57; Sample: Older adults with epilepsy (21 men, 36 women); Age: >65	Setting: USA, Southern Arizona. Recruited through flyers, public education sessions and referrals
Mlinar et al.	2016	Persons with Epilepsy: Between Social Inclusion and Marginalisation	Explore subjective experiences of social inclusion in people with epilepsy in Slovenia	Individual semi-structured interviews; Analysed by content analysis using coding frames	Sample size: n=11; Sample: Adults (8 women, 3 men) with epilepsy; Age: 27-64 years	Setting: Community setting in Slovenia
Keikelame & Swartz	2016	"The others look at you as if you are a grave": a qualitative study of subjective experiences of patients with epilepsy regarding their teatment and care in Cape Town, South Africa.	Describe the subjective experiences of how people with epilepsy in an urban township in Cape Town understand their illness.	Individual semi-structured interviews; Analysed using thematic analysis.	Sample size: n= 12; Sample: People with epilepsy in Cape Town (8 males, 4 females); Age: >18 years	Setting: Community based in urban township in Cape Town, South Africa.
Collard & Ellis-Hill	2016	'I'd rather you didn't come': The impact of stigma on exercising with epilepsy	To explore the barriers to exercise for people with epilepsy. To provide a deeper understanding of how stigma is felt and enacted with a view to considering how it can be reduced.	Focus groups and individual semi-structured interviews; analysed using constructionist grounded theory.	Sample size: n=11; Sample: People with epilepsy ; Age: >18 years	Setting: Community setting in Bournemouth, UK.
Pembroke et al.	2017	Becoming comfortable with "my" epilepsy: Strategies that patients use in the journey from	To understand how people become comfortable and how	Individual interviews; analysed using grounded theory	Sample size: n=49; Sample: People who felt comfortable with their epilepsy; Age: >18 years	Setting: Community setting in Ireland

		diagnosis to acceptance and disclosure	they constructed their epilepsy.			
Crooks et al.	2017	Mind the gap: Exploring information gaps for the development of an online resource hub for epilepsy and depression	To identify current gaps and barriers to current online resources designed for people with epilepsy and depression.	Individual interviews; analysed by content analysis	Sample size: n=10; Sample: People with epilepsy and depression; Age: 27-53 years	Setting: Recruited via local epilepsy registry in Canada
Yennadiou. & Wolverson	2017	The experience of epilepsy in later life: A qualitative exploration of illness representations	To explore the lived experience of epilepsy in later life through older peoples' appraisal of their condition.	Individual interviews; analysed using IPA	Sample size: n=10; Sample: Older adults with epilepsy; Age: >65 years	Setting: Recruited from a Neurological Department in North of England, UK.
Kılınç et al.	2017	The experience of living with adult-onset epilepsy	To explore the experience of living with adult-onset epilepsy	Individual semi-structured interviews; analysed suing IPA	Sample size: n=39; Sample: People with epilepsy onset >18 years; Age: >18 years	Setting: Recruited via epilepsy charity and support group in UK.
Raffaele et al.	2017	Men with adult onset epileptic seizures	What characterises family relations for men with adult-onset epileptic seizures	Semi-structured interviews; analysed using IPA	Sample size: n=5; Sample: Men with adult-onset epilepsy that had undergone temporal lobectomy neurosurgery; Age: 24-45 years	Setting: Recruited via epilepsy charities in Australia
Keikelame, & Swartz	2018	I wonder if I did not mess up....: Shame and resistance among women with epilepsy in Cape Town, South Africa	To provide and in-depth understanding of the ways in which women with epilepsy experience shame and resistance.	Individual semi-structured interviews; Analysed using thematic analysis.	Sample size: n= 12 (4 participant responses related to the research question); Sample: People with epilepsy in Cape Town (8 males, 4 females); Age: >18 years (mean age males 47 years, mean age females 37 years)	Setting: Community based in urban township in Cape Town, South Africa.
Raffaele	2018	A qualitative study exploring family life in men	What characterises family relations for men	Semi-structured interviews; analysed using IPA	Sample size: n=5; Sample: Men with adult-onset epilepsy that had undergone	Setting: Recruited via epilepsy charities in Australia

			with adult-onset epileptic seizures		temporal lobectomy neurosurgery; Age: 24-45 years	
Sarudiansky et al.	2018	A life with seizures: Argentine patients' perspectives about the impact of drug-resistant epilepsy on their lives	To add information about patients' perspectives of drug-resistant epilepsy from a developing nation.	Semi-structured interviews; analysed using thematic analysis	Sample size: n=20 (12 men, 8 women); Sample: Adults with drug-resistant epilepsy; Age: 22-52 years	Setting: Recruited from hospital clinics in Argentina
Molavi et al.	2019	The experiences of Iranian patients with epilepsy from their disease: A content analysis	The experiences of patients with epilepsy regarding stigma.	Semi-structured interviews; analysed using content analysis	Sample size: n=22; Sample: Adults with epilepsy; Age: >20 and <60 years	Setting: Recruited from a neurology clinic in Iran.

Table 3: Critical Appraisal of the Included Studies

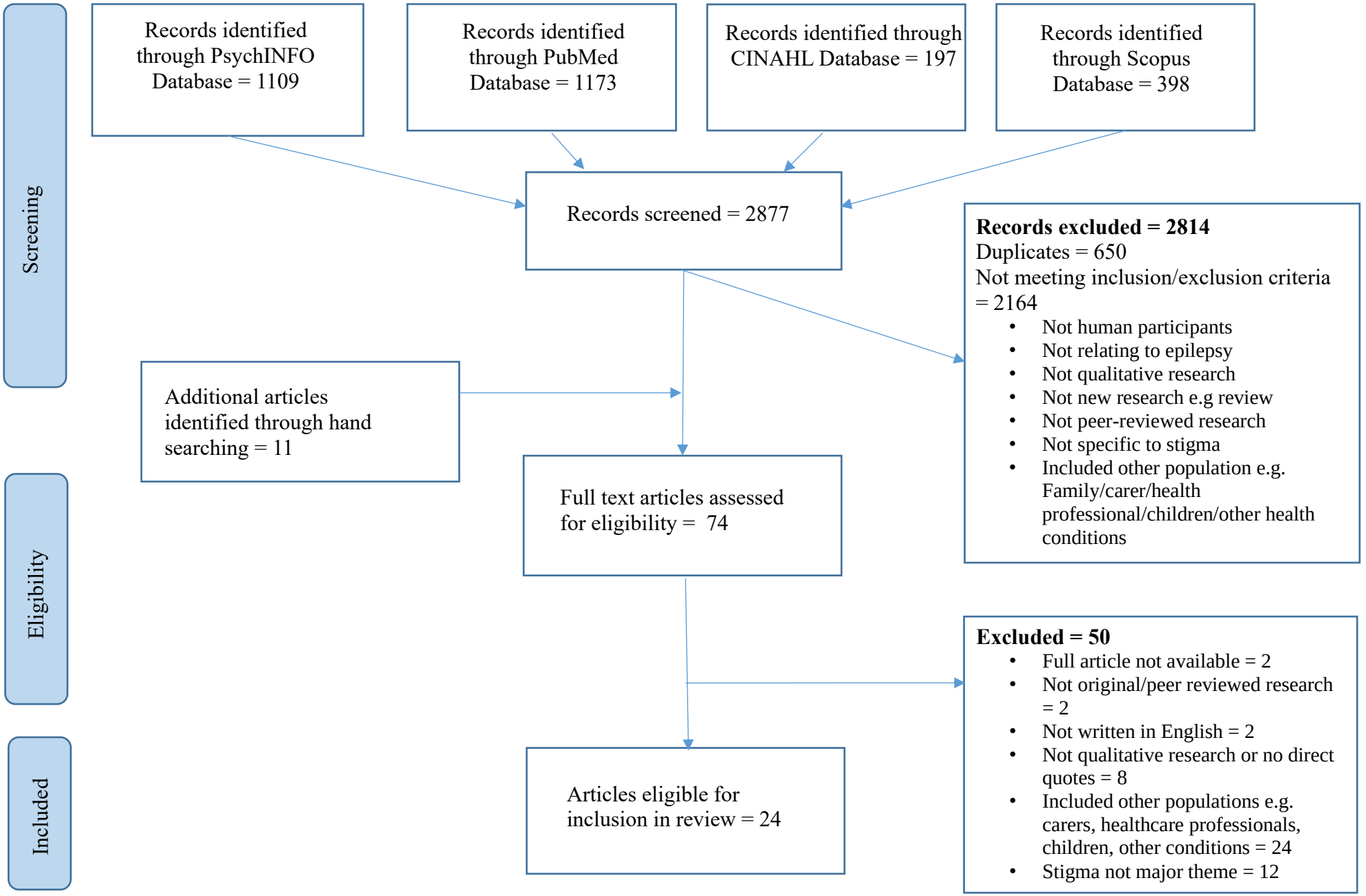
CASP Criteria	Bishop et al., 2002	Paschal et al., 2005	Birbeck et al., 2008	Kilinc & Campb-ell, 2009	Räty et al. 2009	Räty & Wilde-Larsson, 2011	Gauffin et al., 2011	Komola-fe, et al., 2011	Chung et al., 2012	Jacoby et al., 2014	Sonecha et al., 2015	Sleeth et al., 2016
Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the research design appropriate to address the aims?	2	3	3	3	3	3	3	1	3	3	2	1
Was the recruitment strategy appropriate to address the aims?	2	3	3	2	2	3	3	2	2	3	1	2
Were the data collected in a way that addressed the research issue?	2	3	2	2	2	2	3	2	2	3	2	2
Has the researcher/participant relationship been considered?	1	2	1	1	1	1	1	1	1	2	1	1
Have ethical issues been considered?	2	2	3	1	3	2	2	2	3	3	2	2
Was the data analysis sufficiently rigorous?	2	2	2	3	2	3	3	2	2	3	2	2
Is there a clear statement of findings?	3	3	2	3	3	3	3	2	2	3	3	3
How valuable is the research?	3	3	2	3	3	3	3	3	2	3	3	3
Total Score	17	21	18	18	19	20	21	15	17	23	16	16

1 = weak, 2 = moderate, 3 = strong

CASP Criteria	Mlinar et al., 2016	Keikelame & Swartz, 2016	Collard & Ellies-Hill, 2017	Pembroke et al., 2017	Crooks et al., 2017	Yennadiou & Wolverson, 2017	Kılınç et al., 2017	Raffaele et al., 2017	Keikelame & Swartz, 2018	Raffaele 2018	Sarudiansky et al., 2018	Molavi et al., 2019
Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Is qualitative methodology appropriate?	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Was the research design appropriate to address the aims?	3	2	2	3	2	3	3	2	3	2	2	2
Was the recruitment strategy appropriate to address the aims?	2	3	2	2	2	3	2	2	3	2	1	2
Were the data collected in a way that addressed the research issue?	3	3	3	3	2	2	3	3	3	3	2	3
Has the researcher/participant relationship been considered?	1	3	2	1	1	1	3	1	3	2	1	1
Have ethical issues been considered?	2	3	2	3	1	2	2	2	3	2	1	2
Was the data analysis sufficiently rigorous?	3	3	2	3	3	3	2	3	3	2	2	2
Is there a clear statement of findings?	3	3	3	3	3	3	3	3	3	3	3	2
How valuable is the research?	3	3	3	3	3	3	3	3	3	2	3	3
Total Score	20	23	19	21	17	20	21	19	24	18	15	17

1 = weak, 2 = moderate, 3 = strong

Figure 1. Process of selecting papers for inclusion



Appendix 1-A: Definitions of Epilepsy

Conceptual definition of seizure and epilepsy (2005)[1]	An epileptic seizure is a transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain. Epilepsy is a disorder of the brain characterized by an enduring predisposition to generate epileptic seizures, and by the neurobiologic, cognitive, psychological, and social consequences of this condition. The definition of epilepsy requires the occurrence of at least one epileptic seizure.
Operational clinical definition of epilepsy (2014)[2]	Epilepsy is a disease of the brain defined by any of the following conditions 1. At least two unprovoked (or reflex) seizures occurring >24 h apart 2.One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years 3. Diagnosis of an epilepsy syndrome Epilepsy is considered to be resolved for individuals who had an age-dependent epilepsy syndrome but are now past the applicable age or those who have remained seizure-free for the last 10 years, with no seizure medicines for the last 5 years.

[1] Fisher, R. S., et al. (2005). "Epileptic seizures and epilepsy: definitions proposed by the International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE)." Epilepsia 46(4): 470-472.

[2] Fisher, R. S., et al. (2014). "ILAE Official Report: A practical clinical definition of epilepsy." Epilepsia 55(4): 475-482.

Appendix 1-B: Search Terms used in Literature Search

Major Concept (combined by searching with 'AND' across rows)	**Key Words**	**Database (combined by searching with 'OR' across columns)**	**Thesaurus Terms**
Epilepsy	Epilep* or Seizure(s)	PsycInfo	DE "Epilepsy" OR DE "Epileptic Seizures" OR DE "Seizures"
		Pubmed	"Seizures"[Mesh] OR "Epilepsy"[Mesh]
		CINAHL	MH "Epilepsy" OR MH "Seizures"
		Scopus	n/a
Stigma	Stigma or discrimination or "social discrimination" or "social perception" "social adjustment" or stereotyp* or attitude or prejudice or ignoran* or shame or disgrace or dishonour or judgement or attitude	PsycInfo	DE "Physical Illness (Attitudes Toward)" OR DE "Health Attitudes" OR DE "Discrimination" OR DE "Attitudes" OR DE "Prejudice" OR DE "Social Acceptance" OR DE "Social Approval" OR DE "Social Discrimination" OR DE "Social Perception" OR DE "Stereotyped Attitudes" OR DE "Stigma"
		Pubmed	"Social Stigma"[Mesh] OR "Shame"[Mesh] OR "Prejudice"[Mesh] OR "Stereotyping"[Mesh] OR "Social Discrimination"[Mesh] OR "Social Behavior"[Mesh] OR "Attitude"[Mesh] OR "Attitude to Health"[Mesh] OR "Social Adjustment"[Mesh] OR "Social Perception"[Mesh] OR "Taboo"[Mesh]
		CINAHL	MH "Stigma" OR MH "Social Adjustment" OR MH "Social Attitudes" OR MH "Social Norms" OR MH "Social Behavior" OR MH "Social Conformity" OR MH "Social Inclusion" OR MH "Social Values" OR MH "Stereotyping" OR MH "Attitude" OR MH "Prejudice" OR MH "Shame" OR MH "Discrimination"
		Scopus	n/a
Experiences	qualitative or ethnograph or experience or experiences or perception or perceptions or semi-structured or semistructured or "semi structured" or unstructured or in-depth or indepth or face-to-face or structured or guide or	PsycInfo	DE "Grounded Theory" OR DE "Interviewing" OR DE "Qualitative Research" OR DE "Questioning" OR DE "Interview Schedules" OR DE "Interviews" OR DE "Structured Clinical Interview" OR DE "Feedback" OR DE "Life Experiences" OR DE "Experiences (Events)"

	guides or interview or interviews or discussion or questionnaire or questionnaires or focus group or focus groups or survey or surveys or thematic or grounded theory or interpretative or narrative or case study or observation or phenomenology or phenomenological or feedback		
		Pubmed	"Ethnology"[Mesh] OR "Grounded Theory"[Mesh] OR "Surveys and Questionnaires"[Mesh] OR "Narration"[Mesh] OR "Case Reports" [Publication Type] OR "Feedback"[Mesh] OR "Qualitative Research"[Mesh] OR "Focus Groups"[Mesh] OR "Interviews as Topic"[Mesh] OR "Interview" [Publication Type] OR "Interview, Psychological"[Mesh]
		CINAHL	MH "Qualitative Studies" OR (MH "Ethnographic Research" OR MH "Ethnological Research" OR MH "Grounded Theory" OR MH "Phenomenological Research" OR MH "Phenomenology" OR MH "Semi-Structured Interview" OR MH "Interview Guides" OR MH "Structured Interview" OR MH "Unstructured Interview" OR MH "Unstructured Interview Guides" OR MH "Structured Interview Guides" OR MH "Interviews" OR MH "Life Experiences" OR MH "Feedback" OR MH "Narratives" OR MH "Open-Ended Questionnaires" OR MH "Life Histories" OR MH "Biographies" OR MH "Surveys" OR MH "Survey Research" OR MH "Focus Groups" OR MH "Vignettes"
		Scopus	n/a

Appendix 1-C. Summary of Relevant Findings of Each Individual Study

Study Details	Summation of Findings
Bishop, 2002	Applying for a job as a person with epilepsy: overt employer decisions, psychological impact of doubt, fear of disclosure, frustration about what to disclose. Maintaining employment: covert dismissal, hiding epilepsy, epilepsy a deterrent, empathy for witnesses. Factors that enable employment: supportive and knowledgeable employers and colleagues.
Paschal et al., 2005	Financial resources: accessing and adhering to medication and treatment, impact of transport and dependence on others, affording medication, epilepsy putting into poverty. Knowledge about epilepsy: misconceptions (drug abuse), need to educate family, relationships ending, more stigma toward convulsions, mistaking symptoms due to lack of education and not seeking help. Patient-provider communication: better care received from tertiary than primary care, unaware of additional care, dissatisfied with primary care, wanting more than medical care. Social networks and social support: support increasing access to transportation and finance (for medication), improved adherence to medication, family views of surgery, minimal community support (including church), not disclosing epilepsy, wanting church to educate and pray about epilepsy similar to other conditions.
Birbeck et al., 2008	Seizure worries: Shame caused by inadvertent taboo breaking (revealing themselves, indication of husband's regard, urinary/faecal incontinence), accidental injury, intentional injury, fear of sexual assault. Family response to the PWE: supportive families or extreme rejection (physical abuse, in urban regions "sent back to the village"). Role fulfilment: Marital relationships (difficulty finding partner if epilepsy developer prior, married women abandoned or feared abandonment, lost children, sexual rejection leading to poverty and humiliation); Childbearing and rearing (fear children taken, prenatal or paediatric injury leading to ambivalence); Employment (seizure worries placed limitations, rejected if condition known, employment terminated as result of seizure); Social role in community (forced disclosure as result of seizure, social rejection and isolation, ridicule).
Kilinc & Campbell, 2009	Misconceptions vs ownership: public negative misconception as mentally ill or using substances, public lack of awareness leading to not feeling 'normal', lack of own knowledge prior to diagnosis, impact of previous experience, reducing uncertainty of seizures and making adjustments. Avoiding vs sharing: hidden illness, concealing through avoidance and withdrawal, impact of seizures on others, disconfirming negative consequences of seizures, concealment contributing to public misconception, disclosure. Embarrassment vs normalising: confidence, seizures drawing attention, engaging in society, impact on identity, need for education.
Räty et al., 2009	Illness/ Condition related to physical disturbances: chronic illness within the brain, condition associated with seizures, happy could be treated, not dangerous, hope might disappear, disappointment at seizures returning. Mental disturbance related to lack of capacity: something wrong in the brain/head, "disgusting", "queer", fear of exposure, anxious about social events, shame at not being entirely sane, not satisfactory member of society, denial of epilepsy. Handicap related to psychological and/or social aspects: a worry and restriction (including work), impact on relationships and childbearing, sorrow as result of obstacles to partnership, pregnancy and parenthood, guilt at suffering of others, shame and feeling of lower human value. Identity related to being epileptic: internalized, separate category of people, being abnormal, shame at not being normal and causing suffering to others by existing. A punishment: epilepsy result of wrongdoing and searching for explanations, sorrow and guilt at having done wrong.
Räty & Wilde-Larsson, 2011	Living with epilepsy means living a normal life - gaining and maintaining control: Accepting the person with epilepsy (accepting as part of daily life, not letting epilepsy rule, disclosing epilepsy so not to fear seizures, need for supportive family); Taking responsibility (listening to signs of a

	seizure and preparing so not to injure self or others, protecting family from harm by education, positive effects of epilepsy reducing feeling different and feeling normal, changing values becoming more understanding to own and others difficulties). Living with epilepsy means living with focus on the condition - conflict and avoidance or resigning to fate: Struggling with stigma, prejudice and loss of control (restrictions on life and giving up dreams, fearing foetal damage, increasing seizures, avoiding situations of disclosure, being observed and controlled by others including family and work, not having the same rights); Physical fears (injury or side-effects of medications); Psychological fears (being seen as different, judged or seen as different, need for concealment and avoid exposure); Social fears (being dependent and a burden, other's attitudes and knowledge, becoming isolated). Giving up hope of recovery, accepting loss of control: building and losing hope of seizure cessation, fear of exposure, vulnerability and mercy of others during seizures, nightmares about what might happen.
Gauffin et al., 2011	Affecting the whole person: Personal development and fulfilment (developing a different personality, difficulties making friends and meeting partners, lifestyle adjustments, need to plan, giving up on dreams, driving restrictions and reliance on others, restrictions, life requiring more effort, impact on academic success, fatigue, impact on self-esteem); Limitation of potential and responsibility (not allowed, others enforcing restrictions due to ignorance, alienation, difficulty explaining and others not understanding symptoms of epilepsy, mistaken for mentally ill, embarrassment). Influencing daily life: Memory (forgetting leading to embarrassment, impact on relationships and work, impact of seizures and medication); Memory ever-present (more difficult than intermittent nature of seizures, decline); Overcoming memory using strategies (using aids, reminders and routine, remembering medication). Affecting relationships: Family and friends (affecting whole family, family taking care, impact on other's work, sustaining friendships, impact of memory difficulties, not disclosing epilepsy, requiring support for seizures, mutual friendship, disregarded); dependence on others (dependence on relatives, close relationships, asking for help, frustration, fear of separation); Guilt (causing family problems, impact on children, scaring children, keeping promises). Meeting ignorance in society: not helping with seizures, not recognising symbol for epilepsy, teaching others.
Komolafe, et al., 2011	Perception about epilepsy: denial of epilepsy, supernatural or contagion causes, traditional/spiritual treatments before western care, costs of care. Family attitudes and social relationships: supportive vs rejecting, patrilineal distancing, concealment, social isolation, avoiding forced disclosure. Economic consequences: impact on education and future potential, employment restrictions, no financial contribution. Marital prospect and relationships: non-disclosure, separation or divorce, rejection/abuse from relatives, ceased financial assistance, poverty, turn to prostitution. Role fulfilment: difficulty being wives or mothers, limited roles due to fear of injury from seizures, impact on fertility, fear of infecting or injuring their children. Vulnerability or abuse: physical and sexual abuse, part of treatment, sexual assault during seizures, rituals.
Chung et al., 2012	Barriers to employment: losing employment as result of seizure, discrimination at work. Invisibility/need to prove: providing deserving of aid, difficulty gaining financial assistance. Stigma toward people with epilepsy: negative attitudes, social rejection, rejection after disclosure, termination of employment, lack of knowledge in public sector workers, concern regarding caring for someone having a seizure. Psychological burden: medication for depression, lack of fulfilment, loneliness, difficulty maintaining relationships and limited social interaction, shame, frustration and guilt, support groups allowing positive coping strategies and increase social interaction. Restricted activities and socialisation: support groups allow opportunity to safely converse without stigma. Social security and income: dilemma regarding aid or employment, impact on self-esteem and contribution to society, sustainability of financial support, unpredictable termination of employment. Value of support groups: gain knowledge, improve coping, build relationships.
Jacoby et al., 2014	Explaining QOL impacts: the linkage between psychological and social losses: Psychological loss following seizure reoccurrence due to intrusion including loss of control, fear, anxiety, embarrassment, vulnerability and stigma. Social consequences such as loss of job, social activities and family roles. Externally enforced decisions such as family member decisions. Withdrawal behaviours in an attempt to minimise harm based on

	previous experience. Restoring 'normality' and regaining good QOL: Seizure control restoring normality and peace of mind via regaining self-confidence and former social and psychological status. Factors exacerbating loss: Seizure factors. Others' perceptions and responses to epilepsy and seizures, misperceptions and abuse. Public reaction to epilepsy as lack of empathy. Others fear and lack of knowledge. Decision to withdraw. Employment factors. Factors limiting loss: Social and contextual factors limit loss. 'Resources' included personal psychological strategies and practical and emotional support from others. Empathy from others.
Sonecha et al., 2015	Beliefs about cause: African beliefs in supernatural causes (spirit possession), contagious disease (malaria type, airborne or sexually transmitted), related to stigma and shame and rejection of others. Caribbean belief that born with epilepsy, chronic condition and not necessary to conceal, generational differences (older beliefs similar to African). Felt and enacted stigma: African born participants experienced persecution and discrimination, lack of care and social rejection, supernatural belief of self, social outcasts, impact on partnership, abuse as result of seizures, continued shame, stigma and social restriction. Caribbean not experienced discrimination, no impact on relationships, but embarrassment at seizures and impact on work so concealment when applying. Managing fits and social restrictions: Caribbean fear of seizures leading to avoidance and isolation, unpredictability being disabling, restricted activities and isolation. African restricted relationships, family, driving and occupation.
Mlinar et al., 2016	Physical consequences: draining seizures, injury, recognising triggers leading to control, avoiding situations leading to seizures. Emotional consequences: fear (reactions of friends, epilepsy worsening, unpredictability) leading to uncertainty about unpredictability of future, self-confinement and social isolation, scaring others. Social consequences: disclosure impacting on social network, loneliness, rejection, employment implications, discrimination at work, impact on relatives, difficulty finding a partner, empathy for others with health concerns. Manging epilepsy information and social contacts: Strategies (concealment, uncontrolled disclosure, hiding seizures, disclosure in close relationships or to enable help, fear or disclosure and non-disclosure with partners and employers, regrets of disclosure vs surprised by positive reactions). Experience (low self-worth, trusting others, others' fearing epilepsy, hurt at others' responses, distress as result of epilepsy, powerlessness, desperation, insecurity, loneliness, self-confinement, disassociation, fear, dependence on others, anxiety, shame, feeling different, inferior, guilt from reliance on others, life changed, loss of autonomy, relatives dominance).
Sleeth et al., 2016	Felt Stigma: experiencing stigma in daily life, reactions (including fear) of others (particularly to tonic clonic seizures), stereotypes, affecting work and social life, not disclosing, perceived connection with mental state, not experiencing stigma. Enacted stigma: rejection from others, exclusion from social events, overt discrimination, worse in earlier life, others being more supportive. Effects of stigma: lack of disclosure, others not disclosing (including parents), refusing epilepsy diagnosis, avoiding terminology because of stigma, stigma not impacting on life. Reasons for stigma: lack of knowledge, belief epilepsy is contagious, negative stereotypes from previous experience. Addressing stigma: community and patient education to increase knowledge (including explaining it is not contagious or harmful to others), teaching others how to live with stigma to mitigate adverse effects.
Keikelame & Swartz, 2016	Difficulties on routine clinical visits: Access to appropriate care inhibited. "You are not told anything". Need to be educated to understand. Professionals too rushed to listen. Lack of interpreters. Perceived Health care professionals (HCP) factors affecting care: HCPs show lack of empathy, respect, interest and poor listening, training. Disrespectful treatment and lack of required information. Counselling and information needs: Insufficient information about medication and side-effects, sexual problems and pregnancy. Need for support with how to cope with epilepsy and impact on socio-economic circumstances.
Collard & Ellis-Hill, 2016	Disclosure to those in authority: Feeling 'different' outweighed safety aspects. Disclosure not needed. Fear and experience that disclosure results in restriction. Feeling responsible to disclose to protect family. Disclosure to other members: fear of negative impact of disclosure. Hidden illness increases stigma. Negative impact of limitations due to epilepsy. Stigma improves with more knowledge. Lack of understanding: "people just don't

	understand". Hidden illness results in less awareness which results in fear in others and viewed as a "weakness". Negative reactions to disclosure such as distancing, increasing fear and stigma. Sharing understanding to decrease stigma: Teaching others and witnessing a seizure has mixed reactions. Disclosure improving felt stigma but increasing enacted stigma.
Pembroke et al., 2017	Meaning of "my" epilepsy: Emotional reaction to diagnosis including felt stigma "I felt like there was something wrong with me" and enacted stigma. Due to lack of knowledge about epilepsy. Need to adjust life as it "dominate(s)". Reluctant to acknowledge diagnosis. Strategies: Need to manage emotions by learning about epilepsy, meet others with epilepsy and talk about it with someone to gain confidence to practice telling. Being comfortable with "my" epilepsy: A way of interpreting epilepsy diagnosis. Not allowing to alter self-image "it's part of who I am but it's not who I am". Being selective about who to tell. Realising not alone to aid positivity and feel no shame.
Crooks et al., 2017	Fear and anxiety: Not understanding epilepsy. Fear of seizure in public due to public perceptions and stigma. Assuming seizure due to drug withdrawal. Isolation due to staying at home for fear of stigma. Impact on daily living such as driving and employment. Losing yourself: Lack of control. Loss of independence and role. Feeling a burden. Health journey and support: Support from family 'critical'. Peer support so not to feel alone. Having understanding employers. Being positive and accepting. Seeking information: Sought information primarily from health providers but also online and from community organizations. Short healthcare visits made getting information needed difficult. HCP viewed as more credible but also didn't know where else to get information. Online forums helpful for sharing experience but not reliable. Not being able to remember log-in information. Importance of credibility of online information. Epilepsy organisations don't promote events sufficiently. Opportunities and filling a gap: Desire for information to share with others to improve empathy.
Yennadiou & Wolverson, 2017	The power of epilepsy: 'It's terrible… it's awful': Distressing and traumatic experiences as result of physical consequences of seizures, concern for the fear caused in others. They say you can live a normal life but you can't': The impact of society's attitudes: Socially stigmatising condition. Negative lay beliefs result in negative attitudes and ignorance from others. Feeling ostracised and isolated. Feeling discriminated and excluded. Keeping their diagnosis concealed to avoid shame and exclusion. Own fragmented understanding of epilepsy. Concealment feeds stigma "I don't speak about it so maybe that's the problem". Loss of control: Epilepsy takes over life. Seizures take over the body. Multiple restrictions due to epilepsy, not going out alone or avoiding risky situations.
Kılınç et al., 2017	The ripple effect: Epilepsy is "life changing" affecting all areas of life. Loss of independence, inability to drive and choose activities to engage in. Feeling restricted by externally imposed decisions and need for supervision. Benefit of learning about own epilepsy and strategies to put in place to manage. Re-evaluating the future: Epilepsy changed life for the better, "things that I've gained" by adapting plans for the future. Easier with diagnosis earlier in adulthood.
Raffaele et al., 2017	Threat minimisation, self-blame, and social isolation: Contending with many threats to personal functioning as a result of social role marginalisation. Anxiety about relationships. Threat from poor treatment from healthcare providers. Attempting to manage by living as normal life as possible, "as though nothing has happened", hiding epilepsy, relocating. Self-isolation to minimise negative social judgement. Self-blame. Cognitive reconstruction: Trying to make sense of their recovery and what was important for self-management. Returning to valued activity. Supporting others in similar circumstances. Emotional acceptance and wish fulfilling fantasy: self-acceptance improves well-being. Seeing self as a survivor. Using humour. Hoping life will improve. Self-blame: over-loading partner with decisions. Impact on forming relationships. Relationship between self-blame and self-isolation. Not living up to others' expectations for recovery.
Keikelame & Swartz, 2018	Processes of shame of living with epilepsy: Disappointment and regret due to disruption of life. Guilt, anger and shame at burdening others and affecting their relationships "dying might be easier than hurting people". Not being able to fulfil role as mother/grandmother. Shame at

	incontinence which impacts relationships. Resistance strategies against discrimination: Ability to devise individual strategies to resist injustice, prejudice and abuse. Retaliating as strategy against unfair treatment from spouse as result of epilepsy. Fighting back.
Raffaele, 2018	Role marginalization: exclusion from normal life. Siblings embarrassed and minimising contact or isolating which affected happiness. Parents not showing care or concern. Spouse embarrassed to socialise with me. Role dependency: Undue reliance on others. Reduced decisional role in family resulting in enjoyed dependency and happiness. Others overprotecting. Having to rely on others, particularly for transport experienced as negative. Financial dependence resulting in loss of relationship. Not being able to work affecting self-identity. Role Enmeshment: Treated by spouse like a child, particularly for emotional support. Not being able to maintain parent role due to diminished responsibility.
Sarudiansky et al., 2018	Characteristics of the illness: unpredictability of seizures impacting on life "I can't do anything". Interactions with the healthcare system: not having equal access to healthcare and benefits. Doctors not caring. Family members taking to traditional healers. Beliefs about the illness: Medical illness and cause vs 'a defect' and feeling ashamed or anger at having epilepsy. Psychological or supernatural causes "something bad you have done". Beliefs about how other people perceive them: Others prejudiced against them. Called "lazy" or "crazy". Feeling a burden to others. Others over-protective and feeling dependent. Whether to reveal illness, only to minimise risk. Importance of social support for emotional support and navigating healthcare. Self-perception: Accepting epilepsy influences disclosure. Feeling different from others. Not living up to societal expectations. Limiting life achievements such as marriage, parenting or employment aspirations. Not being able to financially support family. Lack of independence and autonomy. Hopeful for a cure. Impact of the illness on activities: Restricted in employment and education which impacts on economy and autonomy. Restrictions on activities.
Molavi et al., 2019	Need for support: Those supported by family experienced more positive reactions from others, continued education and positive mood. Support of important people e.g. doctors, teachers, employers increased quality of life. Those without support experienced many problems. Desire for increased public knowledge, reduction in superstitious beliefs, fewer presentations of fear in media, supported through early education. Defence mechanisms: Trying to hide illness, due to fear of being labelled and deprived. Emigrating where no-one knew them and returning home for family support. Family shame: "my mother and father tried to hide my disease". Superstitious beliefs: Belief of being 'damned' and a punishment for guilt and need for faith healers. Negative feelings: Feelings of shame, guilt, regret and fear. Frightened to be alone, not being accepted, effect on their lives and their children getting the illness. Resulted in depression, low confidence and isolation. Experiences of rejection, deprivation resulting in regret.

Appendix 1-D. Process of synthesis and emerging themes and concepts

Relevant studies (First author)	Key themes, first iteration	Key themes, final iteration (second-order constructs)	Core Concept, first iteration	Core Concept, final iteration (third-order constructs)
Paschal, Kilinc, Gauffin, Komolafe, Sonecha, Sleeth, Jacoby, Pembroke, Crooks, Collard, Molavi	Beliefs about cause/public misconceptions/negative perceptions about epilepsy Ignorance/lack of knowledge about epilepsy/lack of understanding Mental illness/intellectual impairment/lack of capacity Caused by illicit substances/drunk/drugs Superstitious beliefs/possession/witchcraft/contagion	Misconceptions about epilepsy	Misconceptions about epilepsy	Societal negative perceptions of epilepsy result in discrimination and rejection
Sonecha, Birbeck, Raty, Raty & Wilde-Larsson, Collard, Yennadiou	Different from society/societal expectations Taboo/strange/abnormal	Different from society	Different from society	
Birbeck, Chung, Komolafe, Paschal, Mlinar, Collard, Raffaelle, Sarudiansky, Molavi	Experiencing rejection/abandonment/relationships ending/being avoided/distancing/disregarded	Rejected from society	Experiencing discrimination and rejection	
Birbeck, Komolafe, Sonecha, Sarudiansky, Mlinar, Collard, Raffaelle,	Experiencing ridicule/physical abuse/abuse/neglect/harm/cleansing	Experiencing discrimination		
Raty, Raty & Wilde-Larsson, Chung, Birbeck, Sleeth, Yennadiou, Sarudiansky	/Own understanding Punishment for wrong-doing/my fault/deserving of epilepsy/ Superstition/supernatural causes	Own misconceptions about epilepsy	Internalised stigma	Internal attributions of blame lead to negative self-perception and shame
Sonecha, Chung, Raty, Mlinar, Gauffin, Pembroke, Collard, Sarudiansky	Self-perception Feeling different/abnormal/'yucky' Feeling of lower human value/low self-worth/disgusting	Feeling different		
Sonecha, Chung, Raty, Mlinar, Gauffin, Yennadiou, Keikelame, Sarudiansky, Molavi	Emotional reaction/shame/blame/guilt/shame on family	Shame	Shame	
Raty, Raty & Wilde-Larsson, Gauffin, Komolafe, Sleeth, Mlinar, Raffaelle, Jacoby	Fear of harming others/injuring others/responsibility for others Scaring others/	Risk to others		
Komolafe, Raty & Wilde-Larsson, Mlinar, Gauffin, Sonecha, Sarudiansky, Yennadiou, Crooks, Collard, Molavi	Fear of rejection//fear of assault/fear regarded stupid/fear of others' reactions	Fear of others' reactions	Fear of stigma	

Relevant studies (First author)	Key themes, first iteration	Key themes, final iteration (second-order constructs)	Core Concept, first iteration	Core Concept, final iteration (third-order constructs)
Chung, Paschal, Raty, Gauffin, Komolafe., Sonecha, Mlinar, Jacoby, Raffaelle, Keikelame, Sarudiansky, Molavi	Difficulties with relationships/effect on relationships/loss of relationship/fear of rejection Role fulfilment: Marital relationships/unable to marry/fear of divorce/losing parent role Impact on friendship	Role fulfilment: relationships	Role unfulfillment	Impact of stigma on everyday life and associated reliance on others
Komolafe, Gauffin, Birbeck, Raty, Keikelame, Raffaelle	Fear of pregnancy/not able to parent/parenting/feeling a bad mother/not providing children/fear of harming baby	Role fulfilment: parenting		
Sleeth, Birbeck, Bishop, Raty, Gauffin, Mlinar, Jacoby, Raffaelle, Sarudiansky, Molavi	Applying for employment/maintaining employment/limited opportunities Losing work/losing job Poor education/disrupted education/cant access school	Role fulfilment: education and employment		
Bishop, Chung, Pachal, Mlinar, Raty & Wilde-Larsson, Jacony, Kilinc, Crooks, Raffaelle	Diminished life/not being whole/daily restrictions/can't do what others do/impact on daily living/multiple restrictions Unable to drive	Restrictions on daily living	Impact of epilepsy and stigma	
Chung, Gauffin, Raty, Yennadiou, Kilinc, Sarudiansky	Not providing/not contributing/financial implications/unequal rights/not meeting potential	Not contributing		
Chung, Birbeck, Klinic, Raty & Wilde-Larsson, Crooks, Yennadiou, Keikelame, Raffaelle, Sarudiansky,	Relying on others/feeling a burden/requiring support/not wanting to be dependent/burdening others	Relying on others	Dependence on others	
Kilinc, Chung, Sleeth, Mlinar, Raty, Gauffin, Jacony, Kilinc, Pembroke, Crooks,	Loss of control/lack of autonomy Externally enforced decisions/family decisions/external restrictions Feeling powerless/feeling restricted/infantilising/other over-protective	Lack of independence		
Sleeth, Pembroke, Raffaelle, Kilinc, Keikelame, Molavi	Refusing diagnosis/rejecting epilepsy/avoiding the 'E' word/not understanding own epilepsy Accepting epilepsy	Denial of epilepsy	Concealment	Attempts to manage stigma through concealment and avoidance
Gauffin, Komolafe, Sleeth, Sonecha, Mlinar, Klinic, Raty & Wilde-Larsson, Chung, Bishop, Padchal, Yennadiou, Sarudiansky, Raffaelle, Molavi, Collard	Hiding epilepsy/not disclosing/keeping epilepsy secret/concealment/not telling employers Choosing when to disclose/choosing who to tell/practicing telling/avoid explaining Fear of others knowing/disclosure resulting in discrimination Being open about epilepsy	Don't disclose epilepsy diagnosis		

Relevant studies (First author)	Key themes, first iteration	Key themes, final iteration (second-order constructs)	Core Concept, first iteration	
Chung, Birbeck, Klinic, Raty & Wilde-Larsson, Sonecha, Komolafe, Mlinar, Jacoby, Crooks, Yennadiou, Raffaelle	Social withdrawal/self-isolation /avoid relationships/choosing friends Avoiding exposure/preventing judgement/pretending to be normal/ fear of forced disclosure/hiding seizures Decreased independence/restricting life/isolating	Social isolation	Social withdrawal	
Birbeck, Komolafe Paschal, Sleeth, Mlinar, Chung, Bishop, Raty & Wilde-Larsson, Molavi, Keikelame, Pembroke, Crooks, Sarudainsky	Receiving support/supportive family/needing family support/support groups/supportive employers/supporting each other	Support	Support as protective	Support from others is beneficial but dependent on own and others' understandings of epilepsy
Raty & Wilde-Larsson, Kilinc, Jacoby, Crooks, Pembroke, Collard, Yennadiou, Raffaelle, Keikelame	Taking control/managing/self-acceptance/self-care/professional support/resilience/adjustment	Protective factors		
Chung, Gauffin, Sleeth,Paschal, Raty & Wilde-Larsson, Kilinc, Molavi, Sleeth, Crooks, Yennadiou,	Educating others/increased awareness/need for understanding/ignorance/incorrect information Church as source of education/education means acceptance/schools should educate Media misrepresentation	Educating others	Need for education	

Appendix 1-E: Epilepsia – Guidelines for Author

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Epilepsia®
Official Journal of the International League Against Epilepsy

INSTRUCTIONS FOR AUTHORS

Epilepsia is the official journal of the **International League Against Epilepsy (ILAE)**. The Journal publishes original articles on all aspects of epilepsy, clinical and experimental, especially of an International importance. Manuscripts should be the work of the author(s), must not have been previously published elsewhere, and must not be under consideration by another journal.

If you have a question not addressed in these pages then contact the journal at epilepsia@epilepsia.com.

Editorial Policies

(1) The Editors-in-Chief of *Epilepsia* invite manuscripts in all areas of epilepsy-related research, especially if useful for an international audience. Manuscript submission is free. As a general guide, manuscripts will be considered for publication if they contribute significant new findings to the field. The primary aim of *Epilepsia* is to publish innovative and high quality papers that provide clinical and/or basic science insights.

The Editors will make an initial evaluation of all manuscripts to determine whether they provide new important information and in the field, are in the proper format, and are appropriate for the Journal (editorial review). Reports are unlikely to be accepted for publication if they are not based on sound science and/or they provide only incremental knowledge of limited general usefulness. To assist authors in deciding whether to submit a manuscript to *Epilepsia*, we provide the following commonly encountered examples of reports which we are unlikely to publish:

(a) Papers that describe clinical features or epidemiology in a given region of the world that do not provide new insights into epilepsy not already published;
(b) Correlative studies where the sample size is too low to provide statistically sound findings;
(c) Genetic association studies in which the association has already been confirmed;
(d) Investigatory articles describing the application of a new technical variation which is not likely to have clinical utility or impact;
(e) Correlative clinical studies, which are conceived without clear hypotheses and the results of which are of little clinical utility;
(f) Basic research studies that are not grounded in epilepsy relevant hypotheses;
(g) Single group, before-after evaluations of therapeutic interventions and programs that do not include a control group;
(h) Small case series which largely replicate what is already known;
(i) Case reports (highly unlikely to be accepted unless they provide novel findings of theoretical or clinical importance).

Epilepsia will accept, review, and publish studies with negative results, provided that appropriate controls have been used, the study is adequately powered, and the results are important and or useful to others in their search community.

(2) Manuscripts describing original research, and passing the initial editorial screen, will be subject to external peer review. Publication of the data before submission to *Epilepsia* as preprints on servers external to the authors' institution such as arXiv, bioRxiv, PeerJ, and figshare are not allowed; these manuscripts will not be accepted. An abstract of the work may have been published, however, if the material in the manuscript has been presented at meetings and the abstract has been published as part of meeting proceedings. At least two reviews are generally obtained for these submissions; additional reviews may be sought at the discretion of the Editors. Appeals of rejection decisions will be considered by the Editors-in-Chief; decisions of the Editors-in-Chief are final.

(3) In the cover letter, authors should indicate that the material described in the manuscript is the work of the author(s), has not been previously published including as preprint on servers. The authors should also specify that the material included in the manuscript is not simultaneously under consideration by any other journal.

(4) As a condition of publication, *Epilepsia* requires authors to transfer copyright to the ILAE. Authors will be asked to login into Author Services and complete the appropriate license agreement via Wiley Author Licensing Service.

(5) *Epilepsia* complies with recommendations of the International Committee of Medical Journal Editors (http://www.ICMJE.org). Authors are required to include a statement at the end of their manuscript affirming that the work described is consistent with the Journal's guidelines for ethical publication (see below). *Epilepsia* is a member of the

Committee on Publication Ethics (COPE), and we adhere to its principles (http://publicationethics.org/).

(6) Data reporting should follow appropriate checklists and guidelines (e.g., STROBE for observational trials; CONSORT for clinical trials), and other checklists should be consulted for other reports including diagnostic accuracy (STARD), systematic reviews and/or meta-analyses (PRISMA, with systematic review protocol registered on PROSPERO) or neuroepidemiological studies (STROND). Checklists can be downloaded from the following:
STROBE – http://strobe-statement.org
CONSORT – http://www.consort-statement.org/consort-statement/
STARD – http://www.stard-statement.org/
PRISMA – http://www.prisma-statement.org/
PROSPERO – https://www.crd.york.ac.uk/prospero/

Epilepsia encourages authors to share the data and other artefacts supporting the results in the paper by archiving it in an appropriate public repository. Authors should include a data accessibility statement, including a link to the repository they have used, in order that this statement can be published alongside their paper. A global registry, re3data.org, is available to help authors identify relevant research data repositories. *Epilepsia* requires authors to cite data in the format proposed by the Joint Declaration of Data Citation Principles: authors; year; dataset title; data repository or archive; version (if any); persistent identifier (e.g., doi). Source: Data Citation Synthesis Group: Joint Declaration of Data Citation Principles. Martone M. (ed.) San Diego CA: FORCE11; 2014 [https://www.force11.org/group/joint-declaration-data-citation-principles-final].

(7) For animal experiments, the authors need to state that the experiments have been performed in accordance with all applicable national and/or international guidelines/laws. The authors should also provide their allowance number for performing animal experiments when available and should add a statement indicating that the principles outlined in the ARRIVE guidelines and the Basel declaration (http://www.basel.declaration.org) including the 3R concept have been considered when planning the experiments.

(8) Authors are also required to provide full disclosure of any conflict of interest as a part of the submitted manuscript (see Disclosure of Conflicts of Interest in the Manuscript Format section under Manuscript Preparation). Manuscripts that do not conform to these guidelines will not be considered for publication. Discovery of or failure to comply will result in rejection of the manuscript, retraction of the published article, and/or a ban on future submissions by the author(s).

(9) In submitting a manuscript, the submitting/corresponding author must acknowledge that: a) all co-authors have been substantially involved in the study and/or the preparation of the manuscript; b) no undisclosed groups or persons have had a primary role in the study and/or in manuscript preparation (i.e., there are no "ghost-writers"); and c) all co-authors have seen and approved the submitted version of the paper and accept responsibility for its content. The Editors reserve the right to require authors to submit their original data for comparison with the manuscript's illustrations, tables, and results.

(10) Sometimes editors make mistakes. If an author believes an editor has made a decision in error we welcome an appeal. Please contact the editor and in your appeal letter, clearly state why you think the decision is a mistake and set out specific responses to any comments related to the rejection. An appeal does not guarantee a re-review.

TYPES OF MANUSCRIPTS

The following types of material may be considered for publication:

(1) Peer-reviewed papers (to be submitted by uploading online via Scholar One Manuscript Central http://mc.manuscriptcentral.com/epilepsia).

a. Critical Reviews and Commentaries. The Editors-in-Chief encourage submission of reviews and commentaries on topical and controversial issues. Authors planning/proposing such papers should contact the Editors-in-Chief at epilepsia@epilepsia.com before submitting their manuscripts. Authors can also approach one of *Epilepsia's* Associate Editors about possible reviews. While there are no strict length limits on this type of paper, manuscripts generally should be around 5000 words and include a maximum of 100 references. Ample figures and tables are encouraged. Longer manuscripts will be considered at the discretion of the Editors-in-Chief, but justification should be provided by the authors.

b. Full-length Original Research Articles. These articles should be limited in length to 4000 words, 50 references and no more than 6 figures and tables (combined). Additional figures and tables will be permitted at the discretion of the Editors or can be submitted as online only Supporting Information (which will be linked to the online version of the published article). Authors should aim for presenting material clearly and completely, in the most concise and direct form possible; the Introduction should be brief (typically less than 600 words), and the Discussion should be restricted to issues directly relevant to the Results (typically less than 1200 words).

c. Brief Communications. These articles including short studies, small series, case reports, etc. should describe previously unpublished material, including original research and/or clinical observations. The papers are limited generally to 1800 words (excluding the summary), 18 references, and no more than 2 figures and tables (combined). Please note that the Editors may use their discretion to request that brief communications be shortened to a length that they feel is appropriate, and may provide for a larger number of figures and tables if justified.

Brief Communications may be published online only (not in the print version of the journal) depending on their impact. They will appear in a specific issue in the electronic (online) version, and will be identified and described (Short Summary) in the Table of Contents of the printed version of that issue. The online versions will be dealt with by PubMed/Medline and other indexing/citation systems, exactly the same way as print articles; they will be referenced by their DOI number and date of online publication.

d. Controversy in Epilepsy: For emerging areas related to epilepsy care and research for which there is more opinion than high quality data, *Epilepsia* uses the Controversy series as a venue. Authors can propose a pro- and con-position each limited to 2000 words. Contact the editors at epilepsia@epilepsia.com before submitting in this series.

(2) Editorially-reviewed material (to be submitted by email to the Editors-in-Chief at epilepsia@epilepsia.com, except letters and commentaries which should be submitted online at http://mc.manuscriptcentral.com/epilepsia)

Other contributions that do not report original research will be published at the discretion of the Editors-in- Chief, with only editorial review. Such material includes: workshop reports and conference summaries, obituaries, letters/commentary to the Editors (500 word limit, and only exceptionally figures or tables), special (brief) reports from ILAE Commissions or other working groups, and announcements. Such material will usually be published in **Gray Matters**.

(3) Supplements (to be submitted as directed by the Editors-in-Chief)

Supplements, including meeting abstracts, will be published only after advance arrangements are made with the Editors-in-Chief. Guidelines for preparing supplements are given below. Proposal for, and questions about supplements should be directed to one of the Editors-in-Chief (epilepsia@epilepsia.com). Such proposals must be explicitly approved by the Editors-in-Chief, who will also confirm the page rate charge for the proposed supplement.

(4) Special reports: In some cases, special reports from ILAE Commissions or other broadly constituted working groups will be published after peer review. The corresponding author of such papers should confer with the Editors-in-Chief to determine if the full manuscript will be peer-reviewed, or whether only a short version will be considered for publication in *Epilepsia's* Gray Matters (see below).

MANUSCRIPT PREPARATION

General Style Guidelines

Manuscripts are to be submitted (and will be published) in English. Writers not fluent in English should seek assistance to ensure proper grammar and syntax, and to help generate a manuscript organization that facilitates reader understanding. Authors for whom English is a second language may choose to have their manuscript professionally edited before submission, to improve the English. A list of independent suppliers of editing services can be found at http://wileyeditingservices.com/en/. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication. The Editors will not re-write papers submitted in unacceptable English, and will return such manuscripts for revision before sending them out for review.

Use international non-proprietary (generic) names when referring to drugs; avoid proprietary (brand) names. All acronyms should be spelled out at first mention. Spell out numbers below 10 and all numbers that are used to begin a sentence; use Arabic numerals for numbers above 10 and for units of measure. Manuscript text should be double spaced with at least 1 inch margin on all sides using size 12 font. Word limits for each type of submission will generally be enforced unless there are good reasons not to do so. If manuscripts exceed these guidelines, authors should submit a cover letter explaining why the additional length is necessary.

Authors are encouraged to use the most recent terminology of seizures and epilepsy (Fisher et al., 2014) and epilepsy classification of the ILAE (Berg et al., 2010). Studies involving treatments should adhere to ILAE's classification of medically refractory epilepsy (Kwan et al., 2011).

Manuscript Format

a. Critical Reviews and Invited Commentaries

- ❑ **Title Page** (see Full-Length Original Research below)
- ❑ **Summary and Key Words**

  Reviews and commentaries should generally begin with a summary (less than 300 words) of the content. The unstructured summary should provide the reader an outline of the main points of the paper. The Summary should be followed by a list of 3-6 Key Words; please provide Key Words that will assist in the indexing of your article (i.e., make it easy for individuals who are searching PubMed to find your paper). Do not use words already incorporated into your title (those words are picked up automatically by the indexing service).

- ❑ **Body of review**

  There is no designated structure for the body of Reviews or Commentaries. Authors are encouraged, however, to use sub-headings to separate major sections and to facilitate clarity and to use figures and tables to illustrate the key issues of the document.

  Tables, figures, figure legends, references, acknowledgements, statement of compliance with the Journal's guidelines for ethical standards in publishing, disclosure of conflicts of interest, and Supplementary material as for *Full-Length Original Research* (see below)

b. Full-Length Original Research, Special Reports, and Brief Communications

❑ **Title Page**

Include the following information: Full title of the manuscript which generally should be as concise and precise as possible; authors' names (first and last names, middle initial when commonly used by that author); institutional affiliation for each author (use superscripted numbers after each author's name, and a corresponding superscripted number before each institutional affiliation); contact information for the corresponding author (name, address, telephone number, fax number, e-mail address); Key Words for use by abstracting services (same as following summary); number of text pages; number of words; number of references; number of figures; number of tables.

❑ **Summary and Key Words**

Provide a summary of no more than 300 words (200 words for Brief Communications). The summary for Full Length Original Research reports should consist off our sections, labeled: Objective; Methods; Results; Significance. This structured summary should concisely and specifically describe why and how the study was performed, the essential results, and what the authors conclude from the results. To promote brevity, authors may use phrases rather than complete sentences. The summary for Special Reports, Invited Commentaries, and Brief Communications is not structured, but should cover the same topics as the structured summary. The summary (structured or unstructured) should be followed by 3-6 Key Words (see above). A second short summary (less than 100 words) is required for Brief Communications that can be used in the print issue Table of Contents. Submit the second short summary as a Supporting Document.

❑ **Key Point Box**

Include 3 to 5 key bullet points that summarize your article after the main body of text. Please ensure each bullet point is no longer than 140 characters. (Brief Communications do not have a key point box). An example of a key point box can be found on the *Epilepsia* Scholar One Manuscripts website (http://mc.manuscriptcentral.com/Epilepsia); please click 'Instructions and Forms' at the top right-hand corner of the homepage.

❑ **Introduction**

State the objectives of the study clearly and concisely, and provide a context for the study by referring judiciously to previous work in the area. Do not attempt to present a comprehensive view of the field. Provide a statement about the significance of this research for understanding and/or treating epilepsy.

❑ **Methods**

Describe the research methods in sufficient detail that the work can be duplicated; alternatively, give references (if they are readily accessible) to previous comprehensive descriptions. Identify the statistical procedures that were used and the rationale for choosing a particular method, especially if it is not standard.

Reports of experimental studies on humans must explicitly certify that the research received prior approval by the appropriate institutional review body and that informed consent was obtained from each volunteer or patient. Studies involving animals must include an explicit statement that animal care and use conformed to institutional policies and guidelines. When animals are subjected to invasive procedures, details must be provided regarding the steps taken to eliminate/minimize pain and suffering, including the specific anesthetics, analgesics, or other drugs used for that purpose (amounts, mode of delivery, frequency of administration).

If extensive descriptions of methods are needed, provide basic information with in the text and submit supplementary information for online Supporting Information.

❑ **Results**

Results should be reported fully and concisely, in a logical order. Do not repeat methodological details from the Methods section. Where possible, use figures and/or tables to present the data in a clear and concise format. Do not repeat data in the text that are given in a table, but refer to the table. Provide textual explanations for all figures, with clear reference to the figure(s) under discussion. Descriptive information provided in figure legends need not be repeated in the text; use the text, however, to describe key features of the figures. When appropriate, give sample numbers, the range and standard deviation (or mean error) of measurements, and significance values for compared populations.

❑ **Discussion**

Provide an interpretation of the results and assess their significance in relation to previous work in the field. Do not repeat the results. Do not engage in general discussion beyond the scope of the experimental results. Conclusions should be supported by the data obtained in the reported study; avoid speculation not warranted by experimental results, and label speculation clearly. Discuss the significance of the data for understanding and/or treating epilepsy.

❑ **Statistical Methods**

The following guidelines assume familiarity with common statistical terminology and methods. We recommend that authors consult a biostatistician during the planning stages of their study, with further consultations during the analytical and interpretational stages.

1. Analysis guidelines:

- Use robust analytic methods when data are skewed.
- Use Kaplan Meier methods, Cox Proportional Hazards, and mixed models analyses for longitudinal data.

- Account properly for statistical outliers.
- Use exact methods as much as possible in analyses of categorical data.
- Use appropriate correction procedures to account for multiple comparisons, and conduct post-hoc comparisons with statistically appropriate methods.

2. Presentation guidelines:

- Report means accompanied by standard deviations; standard errors should not be used.
- Present results with only as much precision as is appropriate.
- Present confidence intervals, whenever possible, including in figures.
- Describe quantity of missingness and methods used for handling such missingness.
- In general, present two-sided p-values. P-values larger than 0.01 should be reported to two decimal places, those between 0.01 and 0.001 to three decimal places, and those smaller than 0.001 should be reported as $p<0.001$.
- In reporting clinical trials, include a flow diagram, a completed trial checklist, and trial registration information. The CONSORT flow diagram and checklist are recommended (http://www.consort-statement.org/).

❑ **Acknowledgments**

Acknowledge sources of support (grants from government agencies, private foundations, etc.); including funds obtained from private industry. Also acknowledge (consistent with requirements of courtesy and disclosure) participation of contributors to the study who are not included in the author list.

❑ **Disclosure of Conflicts of Interest**

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Journal article published electronically ahead of print version

Reilly C, Atkinson P, Das KB et al. Academic achievement in school-aged children with active epilepsy: A population-based study. Epilepsia Epub 2014 Oct 20.

Journal article In Press

Battino D, Tomson T, Bonizzoni E, et al. Seizure control and treatment changes in pregnancy: Observations from the EURAP epilepsy pregnancy registry. Epilepsia (in press 2013)

Letter

Marucci G. Commentary on the new ILAE classification system for focal cortical dysplasias. Epilepsia 2012; 1:219-220. Letter

Published Abstract

Noe K, Drazkowski J. Safety of Long-Term Video EEG Monitoring. Epilepsia 2008; 59(suppl 7):1.125. Abstract

Book

Shorvon S. Handbook of the treatment of epilepsy. Oxford: Blackwell Publishing; 2005

Chapter in a Book

Fraser RT, Gumnit RJ, Thorbecke R, et al. Psychosocial rehabilitation: A pre- and postoperative perspective. In Engel J (Ed) Surgical treatment of the epilepsies. 2nd Ed. New York: Raven, 1993:669-667

Online

Russo CA, Elixhauser A. Hospitalizations for Epilepsy and Convulsions, 2005: Statistical Brief #46. Available at:http://www.hcup-us.ahrq.gov/reports/statbriefs/sb46.jsp. Accessed February 12, 2011.

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#ce8080	206/128/128	0/50/30/18
#a30234	163/2/52	0/100/60/37
#511d24	81/29/36	42/85/67/60
#f1b682	241/182/130	0/29/50/4
#e37c1d	227/124/29	0/58/100/8
#ffde76	255/223/118	0/11/64/0
#abb47d	171/180/125	13/0/47/27
#67771a	103/119/26	27/0/94/55

Color #	RGB Definition	CMYK Definition
#a1c5cb	161/197/203	25/0/7/16
#5698a3	86/152/163	50/0/14/32
#00545f	0/84/95	100/0/28/64
#002f30	0/47/48	87/34/47/77
#bacfec	186/207/236	25/11/0/0
#0076c0	0/118/192	100/46/0/0
#002157	0/33/87	100/75/0/60
#7a5072	122/80/114	50/73/30/18

Section Two: Research Paper

An exploration of the experiences of self-disgust in people with epilepsy

Word Count: 7978 (excluding title page, abstract, tables, references and appendices)

Rebecca Mayor

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Formatted for submission to the journal "Epilepsy & Behavior"

All correspondence should be sent to:
Rebecca Mayor
Doctorate in Clinical Psychology
Furness College
Lancaster University
Lancaster
LA1 4YG
R.Mayor@lancaster.ac.uk

Abstract

***Aim*:** To illustrate the experiences of self-disgust in people with epilepsy and their understandings about this.

Design: A qualitative study informed by thematic analysis.

***Method*:** Ten adults with epilepsy and uncontrolled seizures were recruited online and participated in a telephone semi-structured interview.

Results: Three themes illustrated the development and experiences of self-disgust in adults with epilepsy and uncontrolled seizures, and how participants attempted to manage this. The first theme described the development of self-disgust as a result of the physical manifestations of seizures but also the experiences of others' disgust reactions to seizures and an expectation of rejection. The second theme described the enduring and often, unescapable experiences of self-disgust, which could be experienced despite the physical reality of seizures. The third final theme illustrated how participants attempted to manage experiences of self-disgust, particularly through avoidance.

Discussion: This study was the first to explore qualitatively the experiences of self-disgust in people with epilepsy. People with epilepsy experience disgust in reaction to the physical symptoms of seizures and these disgust-based feelings appear to become internalised following others' disgust reactions. Avoidance as a strategy to manage self-disgust can be protective but may inadvertently maintain self-disgust.

Highlights

- The present study explored the experiences of self-disgust in adults with epilepsy
- People with epilepsy experience disgust in reaction to the physical symptoms of seizures
- People perceive disgust reactions from others in response to their epilepsy and

seizures which become internalised

- These findings highlight the activation of self-disgust in response to epilepsy and seizures but which appeared enduring
- Participants with epilepsy describe avoidance as a means of managing self-disgust but this strategy may not be adaptive

Keywords: Epilepsy, Emotions, Disgust, Self-disgust

1. Introduction

1.1 Epilepsy and Mental Health

As with other chronic health conditions, living with epilepsy may impact on the mental health of affected individuals [1]. In particular, stress, depression, suicidal ideation and anxiety have been reported to be common among people with epilepsy [2]. Individuals with poorly controlled seizures are two to three times more likely to be diagnosed with depression or anxiety than the general population [1]. Such experiences are important to consider in the management of epilepsy as experiences of anxiety and depression are stronger predictors of poor quality of life in people with epilepsy than seizures [3].

However, living with epilepsy may result in individuals experiencing a range of difficult emotions beyond those associated with anxiety and depression. Indeed, individuals with epilepsy are subject to high levels of stigma [4]. Recent research has also indicated that people with epilepsy are more likely to experience negative self-directed emotions such as shame and guilt, [5] which are associated with higher levels and more severe symptoms of anxiety and depression, as well as poorer quality of life [6]. In addition, qualitative studies exploring the experiences of epilepsy have highlighted the importance of consideration of emotions such as embarrassment in the management of the condition [7]. As a result of such

emotional experiences, individuals may experience increased social avoidance and poorer relationships [8]. Therefore, those interested in helping individuals manage the condition should also consider the diverse range of emotional experiences which may otherwise be unrecognised.

1.2 Disgust and Self-disgust

One emotion which has recently benefited from a surge of research interest is disgust [9]. Far from being 'the forgotten emotion of psychiatry' [10] disgust is considered a universal human emotion, [11] relevant to a wide range of psychological difficulties. Most psychological models of disgust conceptualise it as a negative but adaptive emotion which, via revulsion and rejection, allows for self-preservation through distancing oneself from potential contaminants [9]. This particular model describes four distinct disgust elicitors and their respective functions: core elicitors such as food and body waste products (e.g., faeces, vomit, urine) which protect us from harm and disease; animal-nature elicitors such as sex, death and hygiene that protect our 'soul' and mortality; interpersonal disgust to allow for the avoidance of contact with contaminated others; and moral disgust, elicited by moral violations to protect our social status. However, more recent conceptualisations of disgust propose that it can in fact, be triggered by a wide range of sociocultural factors [12].

In recent years there has also been increased interest into the transdiagnostic construct of self-disgust. Self-disgust is conceptualised as a dysfunctional, rather than adaptive, generalisation of the disgust response, directed towards the self [13]. It has been found to correlate positively with disgust, as evidenced by the high concurrent validity between the Self-Disgust Scale and the Disgust Sensitivity Scale [14].

Until recently, research into self-disgust was still in its infancy. Indeed, both in research and lay language, experiences of self-disgust have often been described by better known self-directed emotions such as shame or guilt, or these may have been used

interchangeably [15], perhaps obscuring the prevalence and importance of self-disgust. Others have described self-disgust as a component of self-criticism [16]. However, self-disgust has now been subject to increased international empirical and theoretical study and a recent mixed-methods review examined the clinical utility of self-disgust [17].

Self-disgust has been conceptually delineated from other negative self-referent emotions such as self-criticism, low self-esteem and shame, mainly through its phenomenological experiences related to disgust and revulsion [12, 18, 19], including the visceral and pervasive nature of self-disgust (often experienced as physical feelings of nausea), as well as distinct disgust-based appraisals [15]. For example, it is possible for individuals to have appraisals that might generate shame or guilt, but not disgust and conversely, appraisals that generate self-disgust (such as "I make other people feel sick") but which do not necessarily generate shame [15]. Furthermore, self-disgust is associated with psychological and behavioural reactions (such as social withdrawal or attempts to cleanse or remove the disgusting self) not evident in other emotions [15, 17]. Shame has theoretically been conceptualised as relating to a sense of the whole self as fundamentally flawed, defective or inferior, initiating an urge to withdraw and hide the self [20-22]. Shame and self-disgust may therefore, have different evolutionary underpinnings [12]. While complex relationships exist between self-disgust and other self-directed emotions, [12] self-disgust has now been demonstrated to represent a meaningful and coherent construct which can be both theoretically and empirically differentiated [17].

Self-disgust has, therefore, been conceptualised as a distinct emotional schema [12, 15]. Emotional schemas can be defined as patterns of associations between perception, emotion, appraisals and cognition [23]. In self-disgust, disgust is directed towards the self and thus involves both disgust-based feelings and cognitive elements [15]. Thus, it is postulated that self-disgust schemas likely develop in childhood, perhaps in response to

disgust based abuse, whereas self-disgust in adulthood is more likely to be in response to a change in the self or how the self is experienced [12, 24].

Increased interest in self-disgust has led to its identification in people with a range of mental health difficulties, including individuals with difficulties with depression, body image and trauma [17] and thus, have implications for the treatments of such. Further, the concept of self-disgust and its role in adaptation to physical health conditions has been evidenced. [25]. Indeed, physical side-effects of cancer treatments, such as nausea or bladder or bowel problems, and thus elicitors of core disgust, were associated with increased psychological distress and mediated adjustment to cancer treatment [26]. However, it has been proposed that self-disgust in physical health conditions might have both beneficial and detrimental effects on outcomes [27] and there is, therefore, the potential for further exploration of this relationship.

1.3 Epilepsy, Disgust and Self-disgust

Self-disgust in relation to epilepsy may be particularly relevant. Firstly, self-disgust is likely to be culturally influenced and determined according to social norms of what is appraised as disgusting [13]. Indeed, disgust propensity (proneness to be disgusted) has been found to be associated with negative attitudes toward people with cancer [28].

Given that epilepsy is a disorder associated with very visible behavioural consequences of seizures, individuals with epilepsy may have to experience core disgust-inducing stimuli (such as convulsions, or incontinence) that could result in the activation of the self-disgust schema. Indeed, Reynolds and colleagues [29] propose that the symptoms of physical illness mean that exposure to disgust-elicitors is commonplace and, as a result, activation of the self-disgust schema is unavoidable.

Furthermore, the self-disgust schema is likely to develop in response to others' reactions to one's self and behaviour [12]. Epilepsy remains associated with a range of

misconceptions and myths [30] and high levels of illness-related stigma are reported [31]. For example, epilepsy has been considered to be caused by an "unclean dumb and deaf spirit" (p. 12) [32], illustrating negative held beliefs about the nature of epilepsy. Individuals with epilepsy may therefore have to confront a wide range of disgust-inducing stimuli, such as being perceived as contaminating and being socially stigmatised [33]. Disgust responses have been shown to be automatically activated in onlookers due to the perceived risk of contamination, despite a genuine lack of such pathogens [34], as demonstrated in perceptions of obesity [35]. It is possible, therefore, that self-disgust in epilepsy may be an important mechanism involved in the high levels of social avoidance reported in this population [36]. Parents of children with disfigured faces report avoiding taking their children out in public due to anticipated disgust reactions of others [37]. Indeed, disgust-induced social avoidance has been evidenced in people with bowel problems.

1.4 Current Research Question

The theoretical explanation of whether and how self-disgust might be experienced by individuals with epilepsy is yet, unexplored. Such understanding would provide insight into the management of epilepsy and associated psychological distress.

The current study addresses this gap in the literature by exploring first-hand perspectives of people with epilepsy. Using a qualitative methodology, the primary aim of the current study was to explore the experiences of self-disgust in people with epilepsy and their understandings about this.

2. Method

2. 1 Design

Qualitative methodologies allow for in-depth exploration of a small sample of participants' experiences allowing for a richer understanding of subjective perceptions and complex experiences [38]. A qualitative approach was chosen as the most appropriate

methodology to address the research question as it would provide opportunity to explore participants' experiences of self-disgust in epilepsy, an area which has yet to be researched.

Thematic analysis is an established method of qualitative analysis [38]. It allows for a systematic approach to the identification of themes and summarises patterns of data across the dataset that are important to a specific research question [39]. Thematic analysis can be a useful approach to explore individuals' experiences of a novel phenomenon and was therefore chosen as the most appropriate methodology for the current study.

2.2 Procedure

The necessary ethical approval for research carried out within the National Health Service (NHS) was received prior to commencement of the study. Recruitment to the research study was via two sources: a single-centre NHS epilepsy service and a leading national epilepsy charity. Recruitment was promoted by staff and by electronic media such as the charity's website, social media and email, as well as more traditional routes such as newsletters and word of mouth. Potential participants were invited to complete a consent form, provide demographic details and complete the Self-Disgust Rating Scale (SDS) [14] either online or via post. Participants were made aware that a proportion would be invited to further take part in an in-depth qualitative interview and consent for this was gained at the time.

To identify participants for whom self-disgust might be most relevant, those with the highest scores on the SDS were invited to interview. Scores on the SDS can range from a possible score of 12 to 84. Only participants who scored greater than 31 were considered for inclusion in the interview element of the research. This represented a score of more than one standard deviation above the mean according to a previous non-clinical sample ($M = 29.8$, $SD = 1.2$)[14]. This is consistent with an approach adopted in a study exploring self-disgust within a different population [15]. As specified in the approval of the study, interviews could

take place face-to-face or over the telephone. Due to practical restrictions and participant preference, all interviews took place over the telephone. Prior to the interview taking place, all participants were informed that they could stop the interview at any time and could withdraw their data from the study up to two weeks following the interview. At the end of the interview the researcher ensured that the participants were not feeling distressed and debrief information was provided, including details of where to seek further support if required.

Interviews were conducted according to a semi-structured schedule (see Appendix 2-A). This was based on a previous study which qualitatively explored the experiences of self-disgust in females with depression [15], but which was adapted for the current research study. This allowed for discussion of background to epilepsy and seizures, experiences of emotions including self-disgust, as well as the relationship between them. Although the interviewer followed the schedule, interviews were led by the participants and how they discussed their experiences in line with the research question. Therefore, parts of the schedule may have been elaborated on if it was believed by the researcher to be important to the participant. This is consistent with data collection methods appropriate for thematic analysis [14].

2.3 Participants

Forty-three participants completed the SDS and consented to take part in the research. All did so via the online source. The median score on the SDS was 50 (IQR = 43-59). A total of 38 participants (88%) scored above the chosen cut-off, suggesting high rates of self-disgust compared to a normative sample [14]. Of these, 10 participants took part in a follow-up in-depth interview. Participants were allocated pseudonyms chosen by the researcher to maintain anonymity. The size of the sample reflected the qualitative thematic approach taken in which the in-depth exploration of the experiences of a small number of participants is

preferential [40] and is consistent with the number of participants recruited in other published research using thematic analysis [41].

Participants were aged 16 years or over (and thus expected to be under the care of adult healthcare services) and self-identified as having received a diagnosis of epilepsy and experienced at least one seizure in the last twelve months. Participants were required to speak English, as it was preferred that the speaker and interviewer be fluent in the same language, and did not have communication or learning problems of sufficient severity to prevent providing informed consent or taking part in an in-depth interview. Information on participant demographics was collected from the participants at the time of consent and included age, gender, type of epilepsy diagnosis, and duration since this diagnosis was received.

Participant demographics are displayed in Table 1. The median participant age was 30 years (IQR = 26-43). The median duration of epilepsy was 10 years (IQR = 3-20).

- Insert Table 1 about here -

2.4 Data analysis

The analysis conducted in this study was consistent with the six-stage approach to thematic analysis described by Braun and Clarke [38]. This approach allows for a flexible but systematic way of gathering, analysing and conceptualising qualitative data but which also encourages the researcher to be reflexive and make their epistemological and other assumptions explicit. The approach involves six phases: 1. Familiarising with the data. 2. Generating initial codes. 3. Searching for themes. 4. Reviewing Themes. 5. Defining and naming themes. 6. Producing the report. For additional guidance, a practical example of conducting trustworthy thematic analysis was consulted [42].

An inductive approach to the analysis was adopted. This aimed to analyse the data in a way that was strongly linked to the data itself rather than trying to fit this within a pre-

existing framework or the researcher's preconception [43]. In line with guidance, interviews were transcribed verbatim by the researcher, which aided becoming familiar with the data. All transcripts were re-read and initial thoughts about the dataset were noted in a reflective log. Codes were then derived directly from the data, working systematically through all transcripts, giving equal attention to each [38]. Important sections of text were highlighted, and labels attached. Codes were derived at the semantic level, to reflect the explicit data itself, as opposed to the latent level which aims to describe concepts and assumptions which might be underpinning the data [38]. All codes and associated text were collated in a spreadsheet and organised into themes by considering the relationships between them. Initially a 'miscellaneous' theme was held so that potentially relevant data was not prematurely abandoned [44]. Initial themes were revised by revisiting the transcripts and refining codes, and the development of themes was carried out by reconsidering the relationships between them. At this stage, themes can be refined, combined, separated or abandoned [44]. The interpretation of themes continued during the writing of the report until the final distinct and separate themes were identified and named.

2.5 Reflexivity

Many quality appraisal tools and criteria can often not be suitably applied to qualitative research [45]. Instead, to demonstrate trustworthy findings, qualitative research and, specifically thematic analysis should be conducted and reported in a rigorous manner [42]. It is, therefore, recommended that qualitative researchers consider issues such as sensitivity to context, rigour, coherence and transparency [46]. Therefore, to demonstrate credibility, these criteria were considered throughout, facilitated by the use of a reflective log.

Thematic analysis is not tied to a particular epistemological position and so is a method that can be flexibly adopted and carried out in accordance with to an individual researcher's stance. However, it is recommended that this is made explicit, so that the

potential influence on the analysis is clear and readers can be assured that findings are coherent and consistent with this position [47].

The epistemological position of the researcher was that of critical realist. Critical realism is ontologically realist. It differs from both positivism (reality is only that which can be empirically known) and constructivism (reality is constructed only through human knowledge or discourse) [48]. A critical realist approach to research therefore, assumes that data is 'real' but that interpretation is needed in order to access the underlying structures of this [49]. Thus, it assumes that an independent reality exists but that this operates independently of our awareness or knowledge of it and thus, can only be fallibly known [50] or 'imperfectly apprehendable' [51]. As such, from a critical realist perspective self-disgust was assumed to exist as a 'real' construct but that current explanations of this are fallible. Thus, attempts to understand 'real' experiences of self-disgust from participants accounts of such, through interpretation based on these existing theories, would also be fallible.

In line with this approach and following guidance on conducting thematic analysis [44], it was considered important to reflect on the preconceptions and knowledge of the researcher and the potential impact of herself on the data collection and analysis. Assumptions were likely to be influenced by the researcher's prior clinical experience of working with this population and awareness of the self-disgust literature. Furthermore, it is acknowledged that identification of participants using the SDS may have further impacted on participants' expectations of the research and thus, demand characteristics were important to consider.

Within thematic analysis, researcher judgement is required to decide on themes as part of the analysis. Thus, a critical realist approach acknowledges the inevitable and inescapable impact of the researcher's experiences, beliefs and assumptions on the data [38]. As such, the researcher assumed that themes did not passively 'emerge' from the data but that

these were actively constructed, according to the researcher's assumptions and informed by the literature [52]. However, in attempts to remain consistent with the inductive approach and limit the impact of such factors on the interpretations made, the researcher, attempted to remain aware of her influence at all stages of the research. Steps were taken to mitigate against this as much as possible through the use of a reflective log and discussion in supervision with a more experienced researcher. Notes were made to track reflections and lines of enquiry following individual interviews and the analysis process [53]. Use of language was also considered, for example, attempting not to ask leading questions during interview and taking care not to take examples out of context during analysis. To support this, all themes were evidenced by direct quotes. Further, an audit trail of the analytic process is provided, allowing readers to judge the reliability of interpretations, by the possibility of tracing the development of themes from raw interview data, to theme identification and the final presented themes.

3. Results

Three key themes were identified from analysis of the data: Being an outsider: "The feeling of being a bit of a freak"; The unescapable presence of self-disgust: "it's a niggling feeling that something's not quite right"; Preventing exposure: "Living a protected life". These are further discussed, and illustrative quotes are provided to support the author's interpretations.

3.1 Being an outsider: "The feeling of being a bit of a freak"

In this first theme, participants described the difficulty in experiencing the physical symptoms of seizures were found to be disgusting. Participants described others' disgust responses to seizures as being inevitable and thus the difficulty experienced in others witnessing them. Subsequent negative reactions of others led participants to feeling stigmatised, internalising disgust and anticipating further negative appraisals and rejection.

All participants described the physical symptoms of seizures which they experienced as unnatural, dangerous, and posing threat to health as one participant explained:

> my whole body goes really rigid, really straight, then I start the jerks. Then I start slavering and loads of foam are coming out of my mouth. They say I make piggy type noises. I wee myself as well, which is the worst bit, and then I just move around all over the floor and smack my head on the ground usually, cause quite a few injuries and blood and bite my tongue, things like that. And my eyes, it's really freaky because I don't close my eyes for some reason. My eyes stay wide open and I'm just staring into nowhere, like into space (Gemma)

Gemma's description details the numerous disgust-inducing symptoms associated with seizures including core and animal-nature disgust elicitors. Furthermore, symptoms of seizures also appeared to result in moral disgust responses, thus feeling degraded, inferior and of low social status: "I feel disgusted in myself, I mean I wee myself when I fit, for goodness sake, it cannot get much lower than that" (Gemma). While social comparisons are often associated with stigma in epilepsy [4] and related to other self-directed emotions, such as shame and self-criticism [54], here it appeared that seizures were also associated with the activation of a stronger disgust response.

Due to their disgust-inducing nature, participants described expecting their seizures to be appraised as "not attractive" (Laura) to others. Therefore, experiencing seizures in public could be particularly difficult: "like it happened in [UK supermarket] that one time and that was mortifying, I was just like, uh, it was just disgusting in the middle of the aisle and people coming up cleaning after myself, the blood and the wee and, uh, it's just embarrassing" (Sue). As Sue explains, others witnessing the physical symptoms associated with seizures, particularly others being in contact with her bodily fluids, due to their potential contaminating nature, could trigger feelings of social embarrassment and disgust.

Participants therefore reported a fear of others witnessing seizures and appraising them as disgusting: “when I have a seizure and stuff I worry about, I feel like other people would be disgusted” (Laura). This seemed driven by a desire to prevent others’ perceptions of them being associated with their epilepsy which they felt would endure: “I don’t want them to have to see me as person who fits, I want them to see the person before all of these fits, because then they’ll just associate me as disgusting, and they’ll just not get the disgusting images out of their heads” (Katie).

Indeed, participants reported receiving negative feedback from others regarding seizures, having been told they appeared “scary” (Sue), “disturbing” (Neil) and “horrifying” (Gemma) to witness. Therefore, the distress and fear that could be provoked in others at seeing seizures could result in extreme reactions; as one participant explained: “I was told that the girl had stood up and screamed, and one girl had even jumped over the desk to get out of the room because she’d had such a fright” (Harriet). One participant explained how these reactions had the potential to make her feel monstrous: “it sort of makes you feel a bit like when you’re having a fit, you know, you look like a monster” (Anne) and in turn feeling ‘dirtied’ and thus, disgusted in herself due to the impact on others: “it makes you feel more, I don’t know, sort of, dirty if you like and it makes you appreciate the effect you have on, the bad effect you have on people” (Anne). As the common behavioural response to disgust is rejection [15, 55], many participants also described being avoided by others as a result of seizures; as one participant described: “there are times when you have a seizure and people don’t help you, which is quite horrible, like, they avoid you” (Helen).

Participants therefore described that, over time, experiencing the symptoms of seizures, learning of others’ disgust reactions and experiencing discrimination led to “feeling different” (Katie), stigmatised and therefore, an outsider of society: “it’s from those conditions that the feeling of being a bit of a freak comes” (Clare). As a result, perceptions

regarding others' disgust-based appraisals and responses towards seizures could become internalised as described by one participant: "it's other people's perceptions of me that makes me feel disgusted in myself" (Emma). Moreover, these emotional experiences appeared to be new as a result of developing epilepsy and distinct from existing beliefs or difficult emotions experienced in the past: "with these fits it is a completely different feeling to what normal feelings I had up until, prior to that" (Helen). It appeared, therefore, that self-disgust was activated by the development of epilepsy and the internalisation of negative appraisals and responses from others.

Therefore, participants described anticipating further disgust responses from others. For many, these responses were appraised as understandable: "just the visual of the vomiting, the gurning, um, like the stiffening of the limbs, the jerking. I would have a fright if somebody took ill in front of me in that way" (Harriet). Thus, participants described further rejection was to be expected: "why would a lad want to be with me and like, share a bed with me when I do things like this?" (Katie). However, participants also described the on-going realisation of such, as distressing: "yeah I know I look disgusting when it's happening, and I already feel disgusting so I don't need them to kind of, point it out" (Gemma). While some participants spoke of others reacting positively to their seizures, these were usually confined to close family and friends with whom they had existing secure relationships and who perhaps had improved understandings about epilepsy.

3.2 The unescapable presence of self-disgust: "it's a niggling feeling that something's not quite right"

In this subsequent theme, participants described the enduring nature of self-disgust due to the uncertainty of epilepsy. Separation of disgust towards the 'epileptic body' from the 'whole self' was described by some participants, which appeared protective, but which was jeopardised by the risk of further seizures.

All participants described the difficulty of living with a condition over which they felt they had limited control and as such, described a persistent sense of unease: “it’s a niggling feeling that something’s not quite right” (Harriet).

Participants described self-disgust as enduring, beyond acute seizures themselves. Indeed, it appeared that self-disgust could also be activated through memories or reminders about epilepsy without the physical reality of a seizure. Such cognitions alone could re-elicit the physiological responses associated with self-disgust: “it makes me feel sick, physically sick when I think back to that time [referring to a seizure]” (Helen). Furthermore, the risk of further seizures and anticipated responses in others could maintain feelings of self-disgust: “there’s always a fear and that fear is always gonna be that if it does happen it’s gonna be horrible” (Sue). As such, one participant described the psychological impact of the unescapable presence of epilepsy, rather than the physical symptoms, as resulting in specific physiological experiences of sickness and nausea which appeared enduring: “a lot of the time it [having epilepsy] just makes us feel really sick, like nauseous” (Katie).

Moreover, due to the uncertain nature of the condition, participants described the inevitable further negative impact of seizures on others. Participants described negative self-directed emotions in response to the impact of their epilepsy on others, as one participant described: “I just feel so frustrated and angry and disgusted with myself that I’m letting other people down” (Clare). For those participants who were parents, the potential to expose their children to the distressing experience was associated with a deep sense of shame, due to their perceived increased vulnerability; as Sue described: “it’s not something a child, should see”. One participant described feelings of self-disgust resulting from the distress caused as a result of the care required from others during seizures: “I feel disgusted that if I have a seizure then people will have to do that [referring to others offering first-aid during a seizure] and I’ve

called on them to do that" (Neil). The potential impact on others' lives was, therefore, also internalised: "I'm disgusted with me because of what I've done to other people" (Neil).

Interestingly, some participants described a psychological distinction between feelings of self-disgust directed towards the self and the body. This appeared more tolerable and prevented penetration of self-disgust towards the 'whole self' as Helen described:

> Disgusted at my body, just revolted at its weakness, just disgusted at it's pointless, the fact that it couldn't even do a short walk, what was the point in it, what was the point of it even existing, that's what I kept thinking, not me existing, but it existing

Thus, many participants described feeling "betrayed" (Harriet) by their body. One participant described this negative affect as being directed specifically at their brain as dysfunctional: "anger at my brain because that's where it's coming from… I feel angry at that and frustrated and disgusted and think why it's not working in the way it should do" (Harriet). Thus, participants described the desire to remove or distance from the epileptic body, but which was not possible due to ongoing physical symptoms of seizures.

However, this separation between the epileptic body and the self, did not appear possible for all participants. While epilepsy appeared to be the trigger for feelings of self-disgust, this could also become generalised to feelings of self-disgust towards the whole self:

> I'm always thinking, I'm a weirdo, I'm a freak, there's so many words and feelings that I can use to describe myself because, only because of the epilepsy, not in myself, just associated with the epilepsy, and I'm horrible, I'm disgusting, I'm freaky, all of this that and the other (Gemma)

Gemma's use of the first person "I" suggests disgust is directed to her entirety. Interestingly, Gemma was one of the most recently diagnosed participants and this difference may reflect lack of time to adjust to living with the condition. It might therefore be hypothesised that this distinction becomes an effective coping strategy with time.

However, even when this separation was available to participants, this was constantly jeopardised by the inevitability of further seizures which could result in an inconsistency between how one viewed the self and how others might perceive them: “it’s changing the view that I’m presenting to the outside world and I’ve actually got no control over it” (Clare). Therefore, participants’ lack of control over their bodies appeared to maintain self-disgust due to feelings of hopelessness and futility.

3.3 Preventing exposure: “Living a protected life”

This theme illustrates how participants attempted to manage their difficult feelings of self-disgust. Participants described radical steps to avoid further public exposure of epilepsy to protect themselves and others. Participants also described altered self-care behaviours.

Participants described the main way of managing the negative emotional impact of epilepsy, including self-disgust as being through avoidance. Disgust responses of avoidance and rejection are described to be an adaptive response that protect us from harmful contaminants [9]. Indeed, participants frequently described disgust in response to the physical nature of seizures and a desire to distance themselves from the situation:

> All I want to do is get up, no-one will let us stand up. They want to call [an] ambulance. Everyone kind of takes over and I just think ‘oh my goodness I’m putting everyone else out’ and I just feel really disappointed in myself, disgusted. I just feel vile. I literally just want to get up and get out of that room where I am, but obviously I can’t stand up straight away after it, so I’ve got to bring myself round fully (Gemma)

However, this quote also describes Gemma’s desire to remove herself from others who were present and caring for her. As such, avoidance may also be used in attempt to manage the fear of stigma, shame and the perceived distress caused in others, which might be associated with interpersonal disgust. However, due to the nature of seizures, behavioural avoidance strategies were often not possible or ineffective.

Avoidance was therefore also used in attempts to hide further seizures from others. This appeared to be as a result of avoiding "the risk of these things happening publicly" (Clare) and thus limiting the resulting negative reactions of others. One participant specifically described this being in an attempt to avoid the anticipated disgust response of others: "I hide myself away, so people don't witness me being so vulnerable and like, disgusting and vile and horrible" (Gemma). Other participants described hearing distressing stories of people being filmed during a seizure and humiliated on social media. Similar to that described in response to health-related shame and stigma [56], the fear of this happening prompted further social avoidance.

Furthermore, perhaps in response to the anticipated disgust and distress caused to others as a result of witnessing a seizure, participants also described social avoidance as a strategy to protect others: "it's just easier for everyone and I don't have to freak out my friends and they don't have to deal with it" (Anne). Despite this potentially leading to feelings of loneliness, Anne viewed this as "the lesser of two evils". Moreover, participants described purposeful attempts to avoid social interaction with people who were familiar to them: "in a way I'd prefer to take ill in front of strangers than in front of the people I know and that care about me, I suppose. Because you have to face those people again." (Harriet). Potentially, avoidance was, therefore, seen as a protective mechanism to maintain relationships with others.

Participants also described avoidance of places where they had experienced seizures as well as other people who had witnessed them. This often led to participants taking radical steps to avoid these situations and participants reported leaving jobs or ending relationships in an attempt to prevent having to face these situations due to the potential to re-activate negative emotions such as shame and self-disgust: "the thought of having to face people when you've wet yourself in front of them is just, it's a really horrendous feeling" (Helen).

One participant described the visceral feelings of sickness as a result of having to return to the environment in which she had experienced a seizure: “it was just the feeling of being, you know, the wanting to be sick as I walked into the office because I didn’t know what I would be facing” (Sue).

Interestingly, some participants also expressed overt attempts to avoid having to witness their own seizures. Participants described the videoing of seizures, often for medical professionals, but not wanting to view the recordings: “I wouldn’t like to see it… I just think it would be disgusting to watch” (Katie). However, for some this lack of knowledge increased distress: “it’s the not knowing what I look like as well that affects us, cause all I know is what people describe, what I look like, but I can’t actually see it for myself” (Gemma). Again, it appeared that those who had developed epilepsy more recently, and therefore had less time to adjust, found this more difficult than others. In contrast, one participant who had experienced epilepsy for many years reported feeling more comfortable with the appearance of seizures: “now I know what they look like and I can prepare for that and I can explain to people what will happen” (Neil). This appeared to result in an improved sense of control.

Participants described altered self-care behaviours. These were described in attempt to limit further seizures, and thus, the distressing and potentially disgust-inducing experiences. Such strategies were therefore viewed as protective, as Clare described: “you live a protected life, you protect yourself… I will never book in something every day of the week. It’s one way that I cope”. However, participants spoke of this also resulting in negative feelings due to living a restricted life.

In contrast, however, some participants also spoke of feelings of self-disgust leading to lack of self-care. This often resulted in engaging in behaviours which appeared to reinforce the belief that the self was disgusting, for example not showering or brushing their

teeth: “I just feel like I’m not worth it and I’m so gross anyway. I’m just a freak” (Anne). This appeared to be associated with the belief that their disgust was unchangeable due to the chronicity of epilepsy, and thus attempts to present themselves more positively were futile. In this way, self-disgust and lack of self-care appeared to develop into a cycle in which one maintained the other.

However, in an attempt at self-affirmation, some participants spoke of information about epilepsy being helpful. Participants described this knowledge about the medical nature of epilepsy as relieving some of the self-disgust and shame often associated with having the condition, perhaps contributing to the separation between the self and the body previously described: “after all this time I know that’s what it does, I can’t stop it… it’s electrical activity that just takes over” (Neil). This was perhaps related to the individual’s duration of epilepsy in which those who had epilepsy for a longer time were more able to accept the nature of the condition and thus generate increased feelings of self-compassion. For others, receiving support and compassion from friends, family or even pets appeared reassuring and protective against some of the difficult feelings associated with epilepsy, including self-disgust.

4. Discussion

This is the first study specifically to consider experiences of self-disgust in people with epilepsy. As well as other self-directed emotions that have previously been described in this population such as shame and stigma [4], interviews with participants demonstrated experiences of self-disgust associated with epilepsy and uncontrolled seizures. The findings presented three key themes. The first theme described participants’ own reactions and their perception of others’ reactions to their seizures which led to feelings of disgust directed towards the self. Subsequently, the second theme illustrated the enduring and often, unescapable experiences of self-disgust, which could be elicited despite the physical reality

of seizures. The final theme described how participants attempted to manage their difficult feelings of self-disgust, predominantly through avoidance, in attempts to protect themselves and others.

4.1 Disgust and self-disgust in epilepsy

Consistent with the psychological model of disgust as an adaptive emotion to protect us from harm and disease [9], participants described disgust being elicited within, as a result of the physical presentation of seizures and associated symptoms of such, including body waste products. Similarly, participants also described the detection and anticipation of similar disgust responses in others' reactions to their seizures. Participants further internalised others' negative appraisals and disgust responses to their seizures and as a result, anticipated further avoidance and rejection.

While disgust elicitors may be viewed as having an adaptive mechanism [9], self-disgust is conceptualised as a dysfunctional generalisation of the disgust response, directed towards the self [13]. In this study, activation of disgust responses was described in response to seizures. This may be, perhaps beneficial for a period of time, to remove participants from danger or as a protective mechanism from others' disgust responses. However, it appeared that participants internalised these reactions and that self-disgust remained active, beyond acute seizures. Indeed, in this study, participants described a persistent and enduring sense of self-disgust which was described as 'always in the background'. This was associated with visceral experiences of sickness and nausea distinct to self-disgust [17]. However, this feeling could also fluctuate over time, as it was intensified by triggers including further seizures or reminders of epilepsy, consistent with previous qualitative descriptions of self-disgust [15].

Interestingly, due to the unpredictable nature of epilepsy, participants described the lack of control over seizures resulting in feelings of self-disgust as unescapable. Such a

finding may be explained by the theoretical perspective of self-disgust as an emotional schema. Emotional schemas represent interactions between perception, emotion, appraisal and cognition [23] and are hypothesised to be persistent at some levels of consciousness [57]. Thus, participants described a self-disgust emotional schema which was enduring in the background, but which could also be triggered by congruent experiences.

While it has been proposed that self-disgust is likely developed in childhood [13], in the current study no differences were apparent in self-disgust experiences due to the age of onset of epilepsy. However, it has more recently been argued that dysfunctional self-disgust schemas can, in fact, be created in adulthood, particularly in those with a latter onset of chronic, debilitating physical conditions [15]. Indeed, in this study, participants indicated that the self-disgust schema was not only activated by seizures but, initiated and demonstrated in response to epilepsy, whether this developed in childhood or adulthood. Furthermore, the majority of participants in the study did not identify previous feelings of self-disgust or of having experienced epileptic seizures in others. This provides further evidence for the activation of a self-disgust schema only initiated in response to personal experiences of epilepsy.

Self-disgust also appeared to be elicited by the perceived 'disgusting' dysfunctional body or brain. In attempts to tolerate this, participants described a psychological distinction between the 'epileptic body' and the 'whole self'. This is consistent with the psychological reactions to self-disgust described in other populations. Indeed, attempts to dissociate the 'disgusting' self from the rest of one's identity have been described in people with eating disorders [18] and in women with depression [15]. Viewing epilepsy as a dysfunctional brain or body, while having an internal focus, allowed some participants to externalise the blame from their self. This, could in time, allow for acceptance of the lack of control associated with condition. This is consistent with previous literature in the development of an altered

sense of self necessary to adjust to having a long-term health condition [58]. It is proposed that only when all other plausible explanations are considered and exhausted, and with repetitive experiences in daily life, can an altered sense of self around illness be accepted. However, studies focusing on the locus of control in epilepsy suggest that those who attribute their epilepsy to external factors might in fact show poorer psychological functioning than those who accept internal triggers [59]. While for some this distinction between disgust at the 'whole self' and the altered 'epileptic body' appeared protective, it may explain why this was not sufficient to prevent prolonged distress and enduring feelings of self-disgust. Further, due to the neurological and therefore, internal nature of epilepsy, the inability to avoid the body could in turn reinforce feelings of self-disgust.

The dominant approach to managing self-disgust described by the participants in this study was that of avoidance. Social avoidance strategies have been well documented in response to epilepsy related stigma [4]. Participants described engaging in behaviours that they felt were protective, both to prevent further seizures, but also in preventing exposure of their epilepsy that might be distressing to others. It has been proposed that disgust may have a causal link to stigma seen in health conditions such as cancer [28]. Indeed the protective function of self-disgust has been suggested [60]. Theoretically, social avoidance in cancer has been proposed to have beneficial effects both in the short and longer term, [29] for example in the maintenance of relationships. However, differences between health conditions in terms of elicitors of disgust are of important note. Further exploration of the relationship between stigma, disgust and avoidance in epilepsy would, therefore, be of interest.

Furthermore, avoidance may not always be the most effective coping strategy. Indeed, it is proposed that avoidance rather than problem-solving coping may be associated with poorer psychological adjustment to epilepsy [61]. Moreover, the mediating impact of self-

disgust on loneliness and depression has been described [62]. In the current study, participants' social avoidance could also be associated with social isolation. Therefore, self-disgust driven avoidance may in fact, maintain distress, similar to that seen in anxiety disorders [63].

4.2 Limitations

This study has a number of limitations which should be considered within the interpretation of the results reported here.

Due to practical restrictions and participants' preference, all participants took part in telephone interviews. As disgust is associated with distinct visceral qualities, often indicated by facial expression, it is possible that the researcher was unable to pick up on more subtle indications of disgust. Future research may be interested in whether such face to face interviews allow for the identification of additional factors when exploring the experiences of self-disgust.

All participants included in the study were recruited online rather than via a healthcare service. Although participants were informed in the participant information that they were only eligible to take part if they had received a diagnosis of epilepsy from a neurologist, and confirmed this verbally during interview, due to self-identification it was not possible to fully ascertain this information. For this reason, it is possible that the sample reported on here included those with non-epileptic seizures who are likely to have different psychological experiences to those with epilepsy [64] and, therefore, may have had different experiences of self-disgust. Future research may benefit from the identification of participants via healthcare professionals to ensure a validated diagnosis and consider any differences between these populations. It is, however, recognised that many research studies, particularly largescale quantitative studies, may indeed face this challenge [65].

Further, a larger proportion of women self-identified and took part in the study than

men. Subtle differences between these groups were identified but which were not explored due to the small sample and qualitative approach. However, higher levels of self-disgust have been reported in women [66]. For this reason, quantitative studies may therefore be of interest to researchers to explore the impact of gender and other factors on the experiences of self-disgust in people with epilepsy.

4.3 Clinical Implications

The results from the current study suggest that emotional states such as self-disgust could be important to consider in relation to epilepsy and psychological distress. Therefore, assessing for the physiological, behavioural, cognitive and affective states associated with disgust may be important to inform interventions for treatments aimed at improving psychological well-being in people with epilepsy.

Current psychological interventions aimed at improving psychological wellbeing in people with epilepsy have included cognitive, behavioural, and mindfulness-based interventions which have been shown to improve quality of life and psychological well-being [67]. However, it is important that healthcare professionals also understand the influence of self-directed emotions, including self-disgust, that might lead to behaviours such as avoidance in some people with chronic health conditions, including epilepsy. Therefore, they are better placed to recognise and support individuals.

Descriptions from the current participants suggested that duration of epilepsy was a potential factor associated with experiences of self-disgust and subsequent adjustment to the condition. Length of illness can be an important factor in adjustment to physical health conditions [68]. Here, it was apparent that those who had been diagnosed with epilepsy more recently were less resourced to apply coping strategies. As such, it may be of increased importance to consider self-conscious emotions within those earlier in the adjustment journey.

Treatments for associated emotions such as guilt and shame have been described, for example mindfulness and present moment acceptance [27], compassion-focused therapy [54] and exposure therapy directed towards disgust at one's own body [69]. Indeed it has been proposed that emotional components are of key consideration in psychological interventions aimed at reducing self-directed emotions [70]. More recently, experimental work has also suggested that self-affirmation may be helpful in reducing in-the-moment self-disgust [71]. Therefore, interventions that focus on both cognitive and affective processes may have value. However, societal factors, such as participants' perceptions of others' disgust reactions to epilepsy and experiencing discrimination appeared to be key in the development and maintenance of self-disgust. Therefore, similar to recommendations aimed at improving stigma towards epilepsy [72], societal approaches aimed at improving understanding and thus, empathy towards those with epilepsy, as opposed to interventions aimed at the individual, may also be beneficial.

5. Conclusions

This study was the first to explore qualitatively the experiences of self-directed disgust in people with epilepsy and uncontrolled seizures. The results suggest that the discrete emotion of self-disgust is relevant to people with epilepsy. People with epilepsy experience disgust in reaction to the physical symptoms of seizures and these disgust-based feelings are hypothesised to become internalised following others' disgust reactions. Avoidance as a strategy to manage self-disgust can be protective but may not always be possible and may inadvertently maintain self-disgust.

6. References

[1] Tellez-Zenteno JF, Patten SB, Jette N, Williams J, Wiebe S. Psychiatric comorbidity in epilepsy: a population-based analysis. Epilepsia 2007;48: 2336-44.

[2] Verrotti A, Carrozzino D, Milioni M, Minna M, Fulcheri M. Epilepsy and its main psychiatric comorbidities in adults and children. J Neurol Sci 2014;343: 23-9.

[3] Johnson EK, Jones JE, Seidenberg M, Hermann BP. The relative impact of anxiety, depression, and clinical seizure features on health-related quality of life in epilepsy. Epilepsia 2004;45: 544-50.

[4] Jacoby A, Snape D, Baker GA. Epilepsy and social identity: the stigma of a chronic neurological disorder. Lancet Neurol 2005;4: 171-8.

[5] Hennion S, Szurhaj W, Skrobala E, Daviere J, Tyvaert L, Derambure P, Delbeuck X. Experiences of self-conscious emotions in temporal lobe epilepsy. Epilepsy Behav 2019;90: 1-6.

[6] Roper C, Fedio A, Fedio P. B-31 The Experience of Shame in Individuals with Epilepsy. Arch Clin Neuropsych 2019;34: 977-977.

[7] Kerr C, Nixon A, Angalakuditi M. The impact of epilepsy on children and adult patients lives: Development of a conceptual model from qualitative literature. Seizure 2011;20:764-74.

[8] Gauffin H, Flensner G, Landtblom A-M. Living with epilepsy accompanied by cognitive difficulties: Young adults experiences. Epilepsy Behav. 2011;22:750-758.

[9] Rozin P, Haidt J, McCauley CR. Disgust. In: Handbook of emotions, 3rd ed. New York, NY, US: Guilford Press; 2008, p.757-776.

[10] Phillips ML, Senior C, Fahy T, David AS. Disgust – the forgotten emotion of psychiatry. British J. Psych 1998;172: 373-375.

[11] Ekman P. An argument for basic emotions Cogn Emot 1992;6: 169-200.

[12] Powell P, Simpson J, Overton P. An introduction to the revolting self: Self-disgust as an emotion schema. In; for avoidance and withdrawal. In: The Revolting Self: Routledge; 2015: p.1-24.

[13] Maratos F. Cognition and emotion: from order to disorder. In: M. Power, & T. Dalgleish, Psychology Press. Hove: Psychology Press; 2008.

[14] Overton PG, Markland FE, Taggart HS, Bagshaw GL, Simpson J. Self-disgust mediates the relationship between dysfunctional cognitions and depressive symptomatology. Emotion 2008;8:379-85.

[15] Powell PA, Overton PG, Simpson J. The revolting self: an interpretative phenomenological analysis of the experience of self-disgust in females with depressive symptoms. J Clin Psychol 2014;70: 562-78.

[16] Gilbert P, Clarke M, Hempel S, Miles JN, Irons CJBJoCP. Criticizing and reassuring oneself: An exploration of forms, styles and reasons in female students. Br J Clin Psychol 2004;43:31-50.

[17] Clarke A, Simpson J, Varese F. A systematic review of the clinical utility of the concept of self-disgust. Clin Psychol Psychother, 2019;26:110-134.

[18] Espeset EM, Gulliksen KS, Nordbø RH, Skårderud F, Holte A. The link between negative emotions and eating disorder behaviour in patients with anorexia nervosa. Eur Eat Disord Rev 2012;20:451-60.

[19] Simpson J, Hillman R, Crawford T, Overton P. Self-esteem and Self-disgust Both Mediate the Relationship Between Dysfunctional Cognitions and Depressive Symptoms. Motivat Emot 2010;34:399-406.

[20] Tracy J, Robins R. Putting the Self into Self-conscious Emotions: A Theoretical Model. Psychol Inq 2004;15:103-125.

[21] Tangney JP, Dearing RL. Shame and guilt: Guilford Press; 2003.

[22] Lewis M. Shame: The exposed self. New York, NY, US: Free Press; 1992.

[23] Izard CE. Basic Emotions, Natural Kinds, Emotion Schemas, and a New Paradigm. Perspect Psychol Sci 2007;2: 260-80.

[24] Powell PA, Simpson J, Overton P. Reflections on the revolting self: A commentary and further directions. The revolting self: Perspectives on the psychological, social, and clinical implications of self-directed disgust 2015: 243-255.

[25] Azlan HA, Overton PG, Simpson J, Powell PA. Differential disgust responding in people with cancer and implications for psychological wellbeing. Psychol Health 2017;32: 19-37.

[26] Powell PA, Azlan HA, Simpson J, Overton PG. The effect of disgust-related side-effects on symptoms of depression and anxiety in people treated for cancer: a moderated mediation model. J Behav Med 2016;39:560-73.

[27] Reynolds L, Lin YS, Zhou E, Consedine N. Does a brief state mindfulness induction moderate disgust-driven social avoidance and decision-making? An experimental investigation. J Behav Med 2014;38:98-109.

[28] Azlan HA, Overton PG, Simpson J, Powell PA. Disgust propensity has a causal link to the stigmatization of people with cancer. J Behav Med 2020;43:377-390.

[29] Reynolds LM, McCambridge SA, Consedine NS. Self-disgust and adaptation to chronic physical health conditions: implications for avoidance and withdrawal. In: The Revolting Self: Routledge; 2015, p.75-88.

[30] De Boer HM. “Out of the Shadows”: A Global Campaign Against Epilepsy. Epilepsia 2002;43:7-8.

[31] Jacoby A, Wang W, Vu TD, Wu J, Snape D, Aydemir N, Parr J, Reis R, Begley C, de Boer H, Prilipko L, Baker G. Meanings of epilepsy in its sociocultural context and

implications for stigma: findings from ethnographic studies in local communities in China and Vietnam. Epilepsy Behav 2008;12: 286-97.

[32] The History and Stigma of Epilepsy. Epilepsia 2003;44:12-14.

[33] Jacoby A. Stigma, epilepsy, and quality of life. Epilepsy Behav 2002;3:10-20.

[34] Park JH, Faulkner J, Schaller M. Evolved Disease-Avoidance Processes and Contemporary Anti-Social Behavior: Prejudicial Attitudes and Avoidance of People with Physical Disabilities. J Nonverbal Behav 2003;27:65-87.

[35] Park JH, Schaller M, Crandall CS. Pathogen-avoidance mechanisms and the stigmatization of obese people. Evol Hum Behav 2007;28:410-14.

[36] Livneh H, Wilson LM, Duchesneau A, Antonak RF. Psychosocial Adaptation to Epilepsy: The Role of Coping Strategies. Epilep & Behav 2001;2:533-44.

[37] Tanner JL, Dechert MP, Frieden IJ. Growing up with a facial hemangioma: parent and child coping and adaptation. Pediatrics 1998;101:446-52.

[38] Clarke V. Using thematic analysis in psychology AU - Braun, Virginia. Qual Res Psychol 2006;3: 77-101.

[39] Fereday J, Muir-Cochrane E. Demonstrating Rigor Using Thematic Analysis: A Hybrid Approach of Inductive and Deductive Coding and Theme Development. Int J Qual Methods 2006;5: 80-92.

[40] Crouch M, McKenzie H. The logic of small samples in interview-based qualitative research. Social Science Information 2006;45:483-499.

[41] Mlinar S, Petek D, Cotieplak M, Zaletel M. Persons with Epilepsy: Between Social Inclusion and Marginalisation J Behav Neur 2016;10.

[42] Nowell LS, Norris JM, White DE, Moules NJ. Thematic Analysis: Striving to Meet the Trustworthiness Criteria. International Journal of Qualitative Methods 2017:16

[43] Patton MQ. Qualitative evaluation and research methods, 2nd ed. Thousand Oaks, CA, US: Sage Publications, Inc; 1990.

[44] Braun V, Clarke V. Successful qualitative research: A practical guide for beginners: sage; 2013.

[45] Yardley LJ. Demonstrating validity in qualitative psychology; Qualitative psychology: A practical guide to research methods, 2008;2:235-251.

[46] Yardley L. Dilemmas in qualitative health research. Psychol Health 2000;15: 215-28.

[47] Holloway I, Todres L. The Status of Method: Flexibility, Consistency and Coherence. Qualitative Research 2003;3: 345-357.

[48] Fletcher AJ. Applying critical realism in qualitative research: methodology meets method. 2017;20: 181-194.

[49] Willig C. Perspectives on the epistemological bases for qualitative research. 2012.

[50] Willig CJQB. Constructivism and 'The Real World': Can they co-exist? 2016.

[51] Guba EG, Lincoln YSJHoqr. Competing paradigms in qualitative research. 1994;2: 105.

[52] Braun V, Clarke V. Reflecting on reflexive thematic analysis. Qual Res Sport, Exerc Health 2019;11: 589-597.

[53] Cutcliffe JR, McKenna HPJJoan. Establishing the credibility of qualitative research findings: the plot thickens. 1999;30: 374-380.

[54] Gilbert P. The origins and nature of compassion focused therapy. Br J Clin Psychol 2014;53: 6-41.

[55] Olatunji BO, Sawchuk CN. Disgust: Characteristic Features, Social Manifestations, and Clinical Implications. J Clin Psychol Med 2005;24: 932-62.

[56] Dolezal L, Lyons B. Health-related shame: an affective determinant of health? Medical Humanities 2017;43: 257.

[57] Izard CE. Emotion theory and research: highlights, unanswered questions, and emerging issues. Annu Rev Clin Psychol 2009;60: 1-25.

[58] Charmaz K. The Self as Habit: The Reconstruction of Self in Chronic Illness. OTJR: Occup Part Health 2002;22: 31-41.

[59] Asadi-Pooya AA. Determinants of epilepsy surgery failure: aetiology matters. Brain 2016;139: 37.

[60] Rosman S. Cancer and stigma: experience of patients with chemotherapy-induced alopecia. Patient Educ Couns 2004;52: 333-9.

[61] Kemp S, Morley S, Anderson E. Coping with epilepsy: Do illness representations play a role? Br J Clin Psychol 1999;38: 43-58.

[62] Ypsilanti A. Lonely but avoidant—the unfortunate juxtaposition of loneliness and self-disgust. Palgrave Communications 2018;4: 144.

[63] Borkovec TD, Alcaine OM, Behar E. Avoidance Theory of Worry and Generalized Anxiety Disorder. In: Generalized anxiety disorder: Advances in research and practice. New York, NY, US: Guilford Press; 2004, p. 77-108.

[64] Kaplan MJ, Dwivedi AK, Privitera MD, Isaacs K, Hughes C, Bowman M. Comparisons of childhood trauma, alexithymia, and defensive styles in patients with psychogenic non-epileptic seizures vs. epilepsy: Implications for the etiology of conversion disorder. J Psychosom Res 2013;75: 142-146.

[65] Verity D, Eccles FJ, Boland A, Simpson JJJotNS. Does perceived control mediate the relationship between stigma and well-being for individuals with Parkinson's disease? 2020: 116841.

[66] Ille R, Schöggl H, Kapfhammer H-P, Arendasy M, Sommer M, Schienle AJCP. Self-disgust in mental disorders—symptom-related or disorder-specific? 2014;55: 938-943.

[67] Michaelis R, Tang V, Wagner JL, Modi AC, LaFrance WC, Jr., Goldstein LH, Lundgren T, Reuber M. Psychological treatments for people with epilepsy. Cochrane Database Syst Rev 2017;10.

[68] Diefenbach MA, Leventhal H. The Common-Sense Model of Illness Representation: Theoretical and Practical Considerations. Journal of Social Distress and Homelessness 1996;5: 11-38.

[69] de Jong PJ, Vorage I, van den Hout MA. Counterconditioning in the treatment of spider phobia: effects on disgust, fear and valence. Behav Res Ther 2000;38: 1055-69.

[70] Whelton WJ, Greenberg LSJP, differences i. Emotion in self-criticism. 2005;38: 1583-1595.

[71] Powell P, Simpson J, Overton P. Self-affirming trait kindness regulates disgust toward one's physical appearance. Body image 2015;12.

[72] Herrmann LK, Welter E, Berg AT, Perzynski AT, Van Doren JR, Sajatovic M. Epilepsy misconceptions and stigma reduction: Current status in Western countries. Epilepsy Behav 2016;60: 165-173.

Table 1: Demographic details of participants

Pseudonym	**Age (years)**	**Gender**	**Duration**	**Self Disgust Scale Score**
Clare	29	Female	8 years	64
Anne	60	Female	12 years	60
Neil	62	Male	47 years	62
Harriet	22	Female	3 years	60
Laura	31	Female	6 months	57
Katie	24	Female	13 years	57
Sam	28	Male	20 years	71
Gemma	26	Female	1 year	59
Sue	43	Female	23 years	56
Helen	30	Female	3 years	49

Appendix 2-A. Semi-structured Interview schedule

Introduce myself and explain that the purpose of the interview is primarily to talk about their experience of difficult emotions, in particular self-disgust. I will ask a bit about their perspectives on having Epilepsy to help me understand their point of view better.
The interview will be mostly guided by the participant but the guide will be used to structure the conversation. Follow-up questions and prompts will be provided when necessary.

1. Brief background about Epilepsy and current situation

How long ago did your seizures start/ receive the diagnosis?
What happens / how often do they happen?
What impact does having epilepsy have on your life currently? *Are there activities/situations that are difficult as a result of having seizures?*

2. Experiences of difficult emotions and self-disgust

How did you find completing the questionnaire on feelings of self-disgust? *Did you notice any thoughts or feelings as a result of this?*
Can you tell me about your experiences of self-disgust? *I am interested in your personal account. Are there any thoughts or feelings related to your experiences?*
Can you tell me about times when you have felt disgusted with yourself? *Can you think of any specific times in the past? What made you feel self-disgust then? What prompted these feelings?*
How do feelings of self-disgust affect you? *Is there anything you do more of/ less of/ differently?*
How do you manage feelings of self-disgust? *Is there anything you do to cope with/avoid these feelings? Are you able to reduce these feelings?*
How do you feel about your experiences of self-disgust? *Are there any other emotions associated with this? What thoughts do you have about yourself?*
Is there anything that makes you feel more positive about yourself? *I am interested in times or situations when you might feel less self-disgusted. Are there times when you are more confident? What positive thoughts/emotions do you have in these circumstances?*

3. Relationship with seizures

When did your feelings of self-disgust first emerge? *Did you have these before having seizures?*
Have they got more or less over the illness period? *Is there any relationship with the course of your condition?*
What effects do the feelings have on your condition? *What aspects of your behaviour are more affected?*

4. Debrief and sources of support

How did you find talking to me today? *Check that participant is not feeling negative or upset.*
Is there anything that is concerning you that you would like to discuss with somebody? *There are sources of support detailed in the information sheet.*

Appendix 2-B. Example of coded transcript excerpt.

I: I see, yeah, ok. So, why do you think it is that you want to kind of hide away, what thoughts kind of go through your mind about hiding away?	
P: so that nobody can see us do it, cause I don't want people to, I don't know I just, I, like strangers and stuff and them looking at us just thinking, look at the state of that, that's disgusting, you look ridiculous, I don't know, it's just that sort of thing	**Avoiding others see seizure** **Expect others to perceive as disgusting**
I: how would that make you feel about yourself if you thought people were thinking like that then?	
P: I'd be mortified I wouldn't go out, I would fit in front of anybody, I'd lock myself in a bedroom but, luckily nobody actually nobody has said I look disgusting in those words as such, but I think sometimes people do say things that make us feel like, yeah I know I look disgusting when it's happening, and I already feel disgusting so I don't need them to kind of, point it out or people say, ah I'll video it when its happens and stuff	**Mortifying** **Stay at home** **Others words elicit disgust** **Anticipating disgust in others**
I: hmm, what sort of things have people said then that have led you to think that way?	
P: A lot of the time it's "you look really freaky", you look really weird, you look scary, it looks like you're no breathing, its looks like you're staring", a lot of people say that they can't believe my eyes, that my eyes freak them out and, somebody just said "you've weed yourself, how can you not hold your bladder in when you're doing this, there's a big wet patch there now, gonna have to clean it up", or things like that. That's the, the weeing myself is the thing that makes me feel most disgusting	**Physical symptoms freaky,** **Scary** **Others disgust at incontinence** **Incontinence is most disgust**
I: Yeah, what do you think it is about that in	

particular that makes you feels so bad?	
P: because it's not normal, I think, I just don't see it as normal	**Seizures not normal**
I: hmm, ok. So, how does it feel when people talk to you in that way?	
P: I feel like they're trying to, because, I think it's because I ask questions though, so I don't help myself. I have to ask them because I'm so desperate to find out what it looks like and what I'm doing, so then I can try and take control of it, because all my control is took away from us when I fit, so try and regain that control, I ask so many questions, but then obviously you have to give us honest opinions and then, the opinions they give us are describing what it looks like and to me, if I saw somebody who looks like that it's embarrassing and I just feel frustrated and annoyed and dirty and horrible, and I dunno	**Asking others for information about seizures** **Trying to get control back** **How would feel at seeing other fit** **Feels dirty, horrible**
I: yeah, I can understand, it's very similar to what other people have kind of, described as well. And is there anything you can do to help those feelings?	
P: erm, not a lot, there's not a lot I can do about it other than to, just keep diaries, realise when I'm gonna do it, and if I ever think I'm gonna do it I got and shut myself away and hide away somewhere on me own so then I can do it without having to, for others to see me looking like that and, things like that, and then, I dunno just that really	**Hide away to prevent others seeing** **Avoid others seeing**

Appendix 2-C. Example of Theme Development: codes and quotes

Theme Two: The unescapable presence of self-disgust: "it's a niggling feeling that something's not quite right"

Example Codes	Example Supporting Quotes
• Persistent unease • Seizure memories re-elicit disgust • Fear due to unpredictable seizures • Frustration at lack of control over seizures • Impact on independence • Useless because of epilepsy • Disappointment to others • Feeling a burden • Disgusted with body • Betrayed by body • Disgust at damaged brain • Anger at epilepsy • Separation from body	• It's a niggling feeling that something's not quite right • I'm just constantly thinking it's gonna happen • A lot of the time it just makes us feel really sick, like nauseous • It makes me feel sick, physically sick when I think back to that time • Thinking in the back of your mind that there's something in there that could ruin it for you • Disgusted that it might happen at any time and I have no control over that • I think the self-disgust comes from a lack of control • I don't want to ruin everything and let people see me like that and disappoint my whole family and my boyfriend • I don't contribute to anything because really, I'm just getting in the way all the time • I'm disgusted with myself that I'm expecting people to look after me • I know straight away that I've had a fit and everyone's staring at us, I feel absolutely mortified • You feel guilty, you feel sorry. You're frustrated with yourself that this has happened • Disgusted with my body I would say. Betrayed by my body… my body has let me down. It's working against me rather than working with me. • It's wrong that a body can do that to you • Its anger at my brain because that's where its coming from • A feeling of separation as well, you feel very separated from your body, or disconnected from your body

Appendix 2-D. Example of theme development: codes and themes

Example codes	**Developing themes/subthemes**	**Final themes**
Disgust at symptoms of seizures	Disgusting symptoms of seizures Seizures aren't attractive	Being an outsider: "The feeling of being a bit of a freak"
Disgust at incontinence		
Sickness and nausea		
Dirty, Unclean		
Seizures scary for others	Seizures scary to others Experiencing negative reactions from others Avoided/rejected	
Fear in others faces		
Mortified at others reactions		
Disgust at others seeing		
Negative reactions of others to seizures		
Mistaken as being drunk		
Others reinforce own feelings	Internalisation of others disgust Not feeling normal	
Feeling a freak		
Persistent unease	Enduring self-disgust Triggers of self-disgust	The unescapable presence of self-disgust: "it's a niggling feeling that something's not quite right"
Fear due to unpredictable seizures		
Frustration at lack of control over seizures		
Seizure memories re-elicit disgust		
Impact on independence	Lack of control Feeling a burden	
Useless because of epilepsy		
Disappointment to others		
Feeling a burden		
Disgust at others having to care		
Disgusted with body	Disgust with body Disgust with brain	
Betrayed by body		
Disgust at damaged brain		
Anger at epilepsy		
Separation from body		

Escaping after seizure	Avoidance of seizures Avoidance of others	Preventing exposure: “Living a protected life”
Trapped by body		
Preventing others witnessing		
Avoiding social situations		
Limited lifestyle		
Avoiding reminders of seizures		
Fear of social media		
Avoiding seeing own seizures		
Protecting self	Self-care	
Lack of self-care		
Wanting information	Information helpful	

Appendix 2-E: Epilepsy & Behavior – Guidelines for Author

EPILEPSY & BEHAVIOR

AUTHOR INFORMATION PACK

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Section Three: Critical Appraisal

Rebecca Mayor

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

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All correspondence should be sent to:
Rebecca Mayor
Doctorate in Clinical Psychology
Furness College
Lancaster University
Lancaster
LA1 4YG
R.Mayor@lancaster.ac.uk

1. Overview

In this thesis three papers are presented. Paper One summarises the systematic search for, and review of, qualitative studies examining the individual experiences of stigma in adults with epilepsy. Paper Two provides an empirical report of a qualitative exploration into the experiences of self-disgust in adults with epilepsy. This current final paper offers a reflective account of the experience of developing and conducting this research. It aims to discuss the strengths and the limitations of the research project and the potential impact on the findings presented. The plan for dissemination of the findings, implications of the research for clinical practice and personal reflections are also discussed.

2. Strengths and limitations of the research and decisions made

Throughout the process of this thesis, a number of important decisions were made. These decisions had fundamental implications for the research and findings presented. While not at all of these can be discussed in detail, some of the key decisions are presented here with discussion regarding the strengths and limitations they implicate for this thesis.

My interest in this research area stemmed from my clinical experience in working with adults with epilepsy prior to my training. Working into a service specialising in providing psychological support to adults with this condition, I developed an awareness of the possible psychological impacts of the condition. During my training I became aware of the self-disgust literature. The more familiar with this I became, the more I contemplated the relevance of this to people with epilepsy. I therefore approached my academic supervisor who is a key contributor to the self-disgust literature as well as a previous supervisor, a key contributor to the epilepsy literature.

I was particularly keen to consider individual understandings and experiences of this phenomenon and so a qualitative design was considered. Surveys may have allowed for more in-depth investigation of the numeric and demographic details about the phenomenon [1].

However, semi-structured interviews were more likely to provide information about the subjective perceptions of individuals' experiences [2]. In line with my research interest, a qualitative interview design was chosen. However, it was acknowledged that lack of previous research meant that it was unclear whether the research question was relevant. As such, it was decided that a quantitative measure would be helpful to identify participants to whom the research question might be relevant.

Another key factor in this decision was the ontological and epistemological framework from which the research was considered. In the current study, the researcher adopted a critical realist position and therefore an independent 'reality' was accepted to exist, but assumed that this can only be fallibly known [3]. Therefore, through a critical realist stance, qualitative research may allow for the use of interview and other social research methods to explore the interpretations of participants experiences, while also taking into account the social context, constraints and resources available to them. The results reported here are assumed to be one attempt to explain the phenomena under investigation. However, it is acknowledged that other interpretations of participant experiences would have been possible, but that these would be no more or less 'real' or valid. Of key importance was the acknowledgement of the likely influence of the researcher on the research process. The research presented should therefore, be considered according to my, the lead researcher's own background, experience and assumptions. It is acknowledged that my previous experience working clinically with people with epilepsy and my developing research interests, including prior knowledge of the epilepsy and self-disgust literature, would inevitably have an impact on the findings. Expectations that experiencing epilepsy could be associated with psychological distress and that self-disgust would be relevant to the population, are also of important consideration.

A key decision concerning my empirical project was the framework or method in which the interview data would be analysed. Thematic analysis is a method used to identify and analyse patterns of meaning across a data set, the aim of which is to illustrate "the most salient constellations of meaning present in the data set" [4]. Guidelines for conducting this are offered [5]. Similar to that of other modes of qualitative inquiry, thematic analysis involves the researcher increasing familiarity with textual data, coding these data and grouping these codes to identify themes [6]. Although the flexibility of the approach afforded by the absence of a single theoretical framework is often described as a strength, critics have questioned the approach, arguing it is a process contained within many qualitative methodologies, rather than being an approach in its own right [7]. However, since this research was initially conducted, revised guidance has been published for carrying out the refined 'reflexive thematic analysis', alongside a checklist for evaluating the quality of the method [8]. Thus the authors emphasise the importance of the researcher making their approach to the method clear, as well as the assumptions underpinning this [9]. Furthermore, the active role of the researcher is acknowledged, recognising the inevitable impact of the researcher on the data and the need for thoughtful engagement and reflexivity [5].

Due to the critical realist position of the researcher and interest into participant experiences, Interpretative phenomenological analysis (IPA) could have been a suitable methodology to address the research question). IPA is a methodological framework for qualitative research grounded in theories of phenomenology and bound to specific epistemological underpinnings [10]. IPA specifically aims to explore how individual participants make sense of their lived experience [11]. Although parallels can be drawn between the analysis involved in both approaches i.e. the identification of themes, IPA differs from thematic analysis in this manner and through the in-depth analysis of data for one

participant before progressing to the interpretation of patterns of meaning for the data set as a whole [6].

As this was a novel area of research it was uncertain whether the participant group would be homogenous. Therefore, thematic analysis was chosen for its flexibility in its method yet its ability to provide a detailed account of the data. This method would allow for differences across participants to be considered by searching for patterns of meaning across the entire data set.

Grounded theory [12] was also considered as an alternative method of analysis. However, the aim was to identify patterns of experience across participants and not to construct a theory from this. On this basis, grounded theory was not used in the current study.

Following Braun and Clark's [9] guidance for conducting thematic analysis, it is important the researcher makes their assumptions and approach to the method clear in order to demonstrate trustworthiness. Important distinctions are the use of deductive versus inductive and semantic or latent approaches to coding and interpretation and the epistemological and methodological implications of these.

A semantic approach to coding aims to identify themes from the explicit data itself and does not attempt to analyse meaning beyond what has been said. In contrast, a latent approach moves beyond the explicit content of the data and attempts to identify the underlying ideas and assumptions that inform this. A semantic approach was consistent with the critical realist position of the researcher and therefore, aimed to limit interpretation of the transcript data but instead focused on considering the broader meaning and implications of the patterns found across transcripts.

Deductive, 'top-down' approaches to data collection and analysis are directed by existing concepts or ideas. Typically deductive approaches use a more structured interview format and coding often uses a pre-existing coding framework to provide detailed analysis

directed towards specified topics of interest, informed by the existing evidence base [13]. In contrast, an inductive, 'bottom-up' approach is one that it is open to hearing about participants' experiences and aims to ground analysis within the data itself. It is acknowledged that the use of the Self-Disgust Scale (SDS) as way of identifying participants could have been consistent with a deductive approach to data collection and analysis, employing the construct of self-disgust as a conceptual framework. However, the aim of the current research was that of explorative investigation of participant experiences of self-disgust. Therefore, a largely inductive approach was taken. This aimed to avoid analysis driven by the researcher's theoretical interests or pre-conceived analytical frames but instead explore patterns of meaning within the data, across datasets. While it is acknowledged that themes do not simply 'emerge' from the data [9] and researchers can never entirely free themselves from their own experiences and theoretical position [5], attempts were made to mitigate this as much as possible. The researcher was keen to limit the impact of their own beliefs and assumptions through the use of supervision and a reflective log whilst making their assumptions clear.

Emotion research relies on the lay public and the academic community sharing meanings of emotion terms under investigation [14]. One important consideration during the research process was the possible delineation of self-disgust from that of other emotions. This has been found to be distinct empirically [15] but may often be described by other, better known emotions such as guilt or shame [16]. Indeed, lay understandings of disgust have been shown to incorporate a combination of both disgust and anger, whereas the term 'grossed out' may more clearly relate to appraisals patterns that are theoretically distinct to disgust [14]. It is therefore argued that researchers need to be hesitant in assuming that participants' understandings regarding disgust are consistent with the researchers. On recruitment to the research study, participants were aware of the purpose of investigation into

self-disgust and thus, may have been more likely to describe this in their language than would usually be observed [17]. It was therefore of importance that during the research process participants' own interpretations of self-disgust were considered, as well as being aware of my own assumptions and understandings about this. Checking meaning and asking participants to elaborate where necessary to help identify experiences, appraisals and reactions which help to delineate self-disgust was important. Furthermore, ensuring not to take accounts out of context in the data analysis was of particular importance [18]. However, according to the critical realist position of the researcher, it is acknowledged that the findings reported here will have been impacted upon by these factors.

Many of the participants included in the study chose to take part in a telephone interview as opposed to a face to face interviews in the participant's home. This appeared unusual compared to other qualitative studies within this population [19] and phenomenon of interest [16]. Telephone interviews have anecdotally been described to be less favoured than face to face interviewing techniques due to the impact on rapport building and the lack of visual cues and nonverbal contextual data [20]. In the current study this may have particular relevance due to the importance of facial expression in recognising and understanding emotion [21]. Indeed, disgust may be identified by facial or physiological expressions [22], although there is limited evidence for this in self-disgust. It was therefore acknowledged that potentially relevant information from interviews could have been lost due to the lack of non-verbal communication through body language and facial expression.

However, it is argued that telephone interviews may in fact allow participants to feel more relaxed and report more sensitive data [23]. Indeed, a study using qualitative methods described advantages to telephone interviews, including not feeling judged or inhibited, and thus, the authors argued that they are a valid first option (as opposed to face to face interviews) [24]. Moreover, stigmatised or marginalised groups may feel particularly more at

ease during a telephone, rather than face to face interview context and telephone interviews may be preferable during discussion of sensitive or embarrassing topics [25]. Therefore, while this decision may be viewed as a limitation to the study, it may also be considered a strength. The option of telephone interviews in this study allowed for the possibility of participant voices being heard that may otherwise have been missed. Furthermore, in a population in which avoidant coping strategies are common [26], this this may have been perceived as less threatening and participants may have felt more able to discuss self-disgust, arguably a sensitive topic

I was aware that conducting telephone interviews might result in additional challenges and I was conscious to try to make interviews as facilitative and flexible as possible to meet the individual needs of the participants. I was particularly aware of the additional potential need to adapt my communication style. For example, not asking multiple questions at one time, as this can create difficulty in the participant knowing how to answer [27]. Moreover, having epilepsy and taking anti-epileptic medications can be associated with cognitive difficulties [28]. Indeed, I felt my training and clinical experience helped me adapt my communication style and in a way that facilitated the conversation. I recognised that with each participant and in later interviews I felt more confident in my ability to adapt my communication in this way.

A further challenge of not having face to face contact with participants was my decreased ability to recognise and assess levels of participants' distress during the interviews as subtle changes in presentation or evidence of distress was not possible [29]. I was aware of the potential emotional impact of the interview on participants [30]. Therefore it was important that protocols were in place in order to safeguard the participants [31]. However, I was aware that at times I found it challenging to know how much to continue to encourage participants to describe distressing experiences while also being mindful of their level of

distress. In discussion with my supervisor I recognised my tendency to avoid pushing participants to deepen their descriptions for fear of evoking distress. I therefore attempted to explicitly 'check-in' with participants during interviews to ensure how they were feeling and whether they would like a break or were happy to continue. Adopting this approach appeared to support participants to feel able to express emotion in a manageable manner and to feel able to be open and give more detailed answers. At the end of the interview, a number of participants described finding the interview process beneficial as it had been the first opportunity they received to express how they were feeling.

Due to participants self-selecting to take part in the study, rather than being recruited via healthcare professionals, epilepsy diagnoses were not confirmed. It is possible, therefore, that some participants who took part in the study experienced symptoms which resembled seizures but which might be clinically diagnosed as other conditions, such as non-epileptic attacks (NEAs). As participants with NEAs may have different psychological experiences to those with epilepsy [32] they may, therefore, have different experiences of self-disgust. Indeed, participants with NEAs have been described as experiencing increased symptoms of anxiety, low mood, psychosis and post-traumatic stress disorder as well as increased likelihood of having experienced abuse or receiving a diagnosis of a personality disorder [33], many of which have also been associated with increased experiences of self-disgust [34].

Whether or not to provide frequencies of participants who describe experiences relating to certain themes has been debated in qualitative research [35]. While some researchers may choose to provide frequencies, others may instead select statements such "some or "many". After consulting the literature and in line with the assumptions of the researcher and approach of analysis, the latter approach was taken as it is argued that frequency does not necessarily determine value in qualitative research [36].

3. Future research and implications for clinical practice

Given the experiences of self-disgust in people with epilepsy described here, it would be valuable to understand more about this relationship. This is the first study to investigate the relevance of self-disgust in people with epilepsy. Further research would help to substantiate the findings here and could provide further insights into the factors involved in this relationship.

Furthermore, despite the rapidly increasing amount of quantitative research into self-disgust, qualitative exploration of this has received less attention [34]. Further in-depth exploration of this concept in people with other mental health and physical health conditions would therefore aid our understandings about this which may also help to inform treatments.

Psychological interventions have been shown to be beneficial for people with epilepsy [37]. However, the current research indicates that such interventions would benefit from the consideration of self-directed emotions such as disgust. In the UK, the NHS five year forward strategy [38] recommended the increased provision of psychological support for people with long term health conditions. However, the implication of such services has been addressed by existing Improving Access to Psychological Therapies (IAPT) services and, therefore, relies on a cognitive behavioural therapy (CBT) approach. CBT has been found to be effective for the treatment of psychological distress related to chronic health conditions such as pain and chronic fatigue syndrome [39], as well as neurological conditions such as Parkinson's Disease [40]. However. it is possible that CBT may not always be the most effective therapy for supporting people to manage self-directed emotions such as self-disgust. Indeed, on this basis, compassion focused therapy was developed to support people with high levels of shame, self-criticism and disgust [41]. Interestingly, one recent study documented the benefit of self-compassion in developing resilience for managing the psychological impact of epilepsy [42]. A previous study has also demonstrated the effectiveness of

Acceptance and Commitment Therapy (ACT) in the reduction of anxiety and depression, improved quality of life and self-esteem in people with epilepsy [43]. Clinical psychologists may, therefore, be well placed to offer individual psychological interventions aimed at helping people with epilepsy manage the condition and the psychological impact of this.

However, the findings presented here also suggest that individual approaches aimed at correcting cognitions or managing emotions may not fully address the needs of people with epilepsy. It is likely that people with the condition will experience discrimination and the disabling opinions of others. Despite this, these wider societal factors are often ignored, even within clinical psychology. As such, interventions aimed at the individual, as opposed to societal approaches to epilepsy, could be insufficient. The current review and empirical study suggest the need for improved societal understanding regarding epilepsy in order to reduce the stigma and psychological impact of this on the individual. Clinical psychologists may, therefore, also have a key role in the dissemination of such knowledge through research and publication but also in the development and delivery of educational materials designed for this purpose. It is worthy of reflection that a UK epilepsy charity was involved in the recruitment of participants for this study. Such organisations may also have a particularly important role in these interventions, which would be have increased potential influence.

4. Dissemination of findings

The findings of this thesis will be disseminated by a number of strategies. Firstly, according to my training course requirements, I have presented a brief summary of the project at Lancaster University to an audience of staff and trainee colleagues. This presentation will be available on the Lancaster University Doctorate in Clinical Psychology programme website. Secondly, I aim to submit Section One, the systemic literature review to a leading epilepsy journal, Epilepsia. Section Two of the thesis, the research project, will also be submitted for publication in a further epilepsy journal which regularly publishes

qualitative research, Epilepsy & Behavior. Such publications aim to disseminate the findings as widely as possible as both of these peer-reviewed journals are circulated worldwide and, therefore, assist in the dissemination of scientific knowledge in the epilepsy field. Finally, in line with my ethical approval and to disseminate findings as widely as possible, I will also share a brief summary of the research findings with the NHS Trust involved in the research, the charity involved in recruitment and with the study participants.

5. Personal reflections

Throughout the process of writing the thesis, I have attempted to consider how my own values, training and clinical experiences and, therefore, my own personal and cultural assumptions might have influenced the research process. I was aware that such preconceived ideas may have influenced the research process and might, therefore, influence the outcomes. To aid this I regularly made notes in my reflective research journal [44].

During the research process I became aware of the potential ethical dilemma of the difference in my role as a researcher as opposed to a clinician. This is demonstrated by an entry in my reflexive diary:

I found the ending of the interview difficult and I recognised the desire to be able to normalise the participant's feelings and distress. It felt difficult to know that the participant believed there was no appropriate support available and I wanted to offer some words of comfort. The debrief information was helpful in order to signpost the participant but I recognised a feeling of frustration that I couldn't offer more. This reminded me of my original reason for wanting to conduct the research and how this was continuing to influence my thinking. (27/07/2017)

This reminded me of my original interests in conducting research within this area and reflected my frustration at the lack of appropriate psychological support which I believed was often unavailable for people with long-term health conditions such as epilepsy. I therefore

gained awareness throughout the interview process of my desire to provide emotional support to participants, as this would be a fundamental part of my clinical practice. In earlier interviews I found myself wanting to explore and formulate their distress and consider ways I could signpost them to further support, in order to reduce their psychological distress. However, through reflection and in discussion within supervision I acknowledged that I was not in a clinical role and that my role as a researcher was to listen and explore their experiences for this purpose. I was also able to recognise that the clinical skills I had developed during training were still relevant. For example, being aware of risk issues that might warrant further action. The ability to listen to participant stories and summarise this remained helpful to the interview process ensuring that I had a good understanding of participants' experiences, rather than relying on my own interpretations and appeared to allow participants to feel heard and understood. Therefore, during subsequent interviews, I was aware that the dilemma remained present, but I was able to manage this by attempting to ensure that my questions were relevant to the research question.

Overall, the process of this thesis was a difficult one which raised a number of challenges for me. I had not envisaged that the thesis would be as arduous and time consuming to complete. However, due to my personal circumstances, much of the thesis was completed after completion of the taught and clinical elements of clinical psychology training. Therefore, I had to manage the demands of full-time employment in a clinical psychology service, alongside this research. I also recognised the impact of the lack of regular contact with my cohort for support during this period as well as the reduced opportunities for face to face supervision. However, the thesis process has also been a rewarding one, allowing me to develop professional as well as research skills.

6. Conclusions

The systematic literature review explored the important challenge of stigma, faced by people with epilepsy. The research project explored the experiences of self-disgust in people with epilepsy. I believe that, combined, these two individual papers provide additional insights into the psychological experiences of people with epilepsy. They highlight the significant challenges that people with epilepsy experience as a result of the condition, their perceptions of themselves and others and how they develop strategies in order to cope and manage these. I thereby hope that the findings of this thesis will add to the understanding of the psychological impact of epilepsy in clinicians and researchers alike in the hope that the distress caused by the condition might be minimised in the future.

This critical appraisal discusses some of the methodological, practical, ethical and professional challenges I encountered and how I attempted to manage these. I hope that these reflections will be helpful for other researchers considering conducting work with similar populations.

7. References

[1] Silverman D. Researching society and culture. In; 1998, p. 261-274.

[2] Low J. Unstructured and semi-structured interviews in health research. In: Researching health: Qualitative, quantitative mixed methods; 2013, p. 87-105.

[3] Willig CJQB. Constructivism and 'The Real World': Can they co-exist? 2016.

[4] Joffe H. Thematic analysis. Qualitative research methods in mental health psychotherapy: A guide for students practitioners 2012;1: 210-223.

[5] Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3: 77-101.

[6] Howitt D, Cramer D. Introduction to qualitative methods in psychology: Prentice Hall Harlow; 2010.

[7] Nowell LS, Norris JM, White DE, Moules NJ. Thematic Analysis: Striving to Meet the Trustworthiness Criteria. Int J Qual Methods 2017;16: 1-13.

[8] Braun V, Clarke V. Thematic analysis : a reflexive approach. In. [online]: The University of Auckland.

[9] Braun V, Clarke V. Reflecting on reflexive thematic analysis. Qualitative Research in Sport, Exercise and Health 2019;11: 589-597.

[10] Larkin M, Thompson A. Interpretative phenomenological analysis. In: Qualitative research methods in mental health psychotherapy: A guide for students practitioners; 2012, p. 99-116.

[11] Eatough V, Smith JA. Interpretative phenomenological analysis. In: The Sage handbook of qualitative research in psychology; 2008, p. 194.

[12] Strauss A, Corbin JJHoqr. Grounded theory methodology. 1994;17: 273-285.

[13] Nowell LS, Norris JM, White DE, Moules NJ. Thematic Analysis: Striving to Meet the Trustworthiness Criteria. International Journal of Qualitative Methods 2017;16.

[14] Nabi RL. The theoretical versus the lay meaning of disgust: Implications for emotion research. Cognition and Emotion 2002;16: 695-703.

[15] Powell PA, Simpson J, Overton PG. When disgust leads to dysphoria: A three-wave longitudinal study assessing the temporal relationship between self-disgust and depressive symptoms. Cogn Emot 2013;27: 900-13.

[16] Powell PA, Overton PG, Simpson J. The revolting self: an interpretative phenomenological analysis of the experience of self-disgust in females with depressive symptoms. J Clin Psychol 2014;70: 562-78.

[17] Harper DJQrmimh, psychotherapy. Choosing a qualitative research method. 2011: 83-98.

[18] Yardley L. Dilemmas in qualitative health research. Psychol Health 2000;15: 215-28.

[19] Thompson D, Thomas H, Solomon J, Nashef L, Kendall S. Chronic illness, reproductive health and moral work: women's experiences of epilepsy. Chronic Illness 2008;4: 54-64.

[20] Novick G. Is there a bias against telephone interviews in qualitative research? Res Nurs Health 2008;31: 391-398.

[21] Ekman P, Matsumoto D, Friesen WV. Facial expression in affective disorders. 1997;2: 331-342.

[22] Powell PA, Simpson J, Overton PG. An introduction to the revolting self: Self-disgust as an emotion schema. In: The revolting self: Routledge; 2018, p. 1-24.

[23] Oltmann SM. Qualitative interviews: A methodological discussion of the interviewer and respondent contexts. Forum Qual Soc Res 2016;17: 1-16.

[24] Ward K, Gott M, Hoare K. Participants' views of telephone interviews within a grounded theory study. J Adv Nurs 2015;71: 2775-2785.

[25] Drabble L, Trocki KF, Salcedo B, Walker PC, Korcha RA. Conducting qualitative interviews by telephone: Lessons learned from a study of alcohol use among sexual minority and heterosexual women. Qual Soc Work Res Prac. 2016;15: 118-133.

[26] Kemp S, Morley S, Anderson E. Coping with epilepsy: Do illness representations play a role? Br J Clin Psychol 1999;38: 43-58.

[27] Smith JA, Jarman M, Osborn MJQhpT, methods. Doing interpretative phenomenological analysis. 1999: 218-240.

[28] Hermann B, Seidenberg M. Epilepsy and cognition. Epilepsy currents 2007;7: 1-6.

[29] Ekman P, Rosenberg EL. What the face reveals: Basic and applied studies of spontaneous expression using the Facial Action Coding System (FACS): Oxford University Press, USA; 1997.

[30] Drury V, Francis K, Chapman Y. Taming the rescuer: The therapeutic nature of qualitative research interviews. Int J Nurs Pract 2007;13: 383-4.

[31] Draucker CB, Martsolf DS, Poole C. Developing distress protocols for research on sensitive topics. Arch Psychiatr Nurs 2009;23: 343-50.

[32] Kaplan MJ, Dwivedi AK, Privitera MD, Isaacs K, Hughes C, Bowman M. Comparisons of childhood trauma, alexithymia, and defensive styles in patients with psychogenic non-epileptic seizures vs. epilepsy: Implications for the etiology of conversion disorder. J Psychosom Res 2013;75: 142-6.

[33] Lesser RP. Treatment and Outcome of Psychogenic Nonepileptic Seizures. Epilep Curr 2003;3: 198-200.

[34] Clarke A, Simpson J, Varese F. A systematic review of the clinical utility of the concept of self-disgust. Clin Psychol Psychother 2019;26: 110-134.

[35] Maxwell JA. Using Numbers in Qualitative Research. Qualitative Inquiry 2010;16: 475-482.

[36] Pyett PM. Validation of Qualitative Research in the “Real World”. Qual Health Res 2003;13: 1170-1179.

[37] Michaelis R, Tang V, Wagner JL, Modi AC, LaFrance Jr WC, Goldstein LH, Lundgren T, Reuber M. Psychological treatments for people with epilepsy. Cochrane Database of Systematic Reviews 2017.

[38] Clarke V. Using thematic analysis in psychology AU - Braun, Virginia. Qual Res Psychol 2006;3: 77-101.

[39] Price JR, Mitchell E, Tidy E, Hunot VJCDoSR. Cognitive behaviour therapy for chronic fatigue syndrome in adults. 2008.

[40] Cole K, Vaughan FLJP. The feasibility of using cognitive behaviour therapy for depression associated with Parkinson's disease: a literature review. Disorders. 2005;11: 269-276.

[41] Gilbert P. The origins and nature of compassion focused therapy. Br J Clin Psychol 2014;53: 6-41.

[42] Baker DA, Caswell HL, Eccles FJR. Self-compassion and depression, anxiety, and resilience in adults with epilepsy. Epilepsy Behav. 2019;90: 154-161.

[43] Dewhurst E, Novakova B, Reuber M. A prospective service evaluation of acceptance and commitment therapy for patients with refractory epilepsy. Epilepsy Behav 2015;46: 234-41.

[44] Ortlipp M. Keeping and using reflective journals in the qualitative research process. The qualitative report 2008;13: 695-705.

Section Four: Ethics Proposal and Supporting Documentation

Rebecca Mayor

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Word Count: (excluding title page, references and appendices)

All correspondence should be addressed to:

Rebecca Mayor
Doctorate in Clinical Psychology
Furness College
Lancaster University
Lancaster
LA1 4YG
R.Mayor@lancaster.ac.uk

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
Experiences of difficult emotions in people with seizures

1. Is your project research?

(●) Yes ( ) No

2. Select one category from the list below:

( ) 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

( ) Basic science study involving procedures with human participants

(●) Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology

( ) Study involving qualitative methods only

( ) Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)

( ) Study limited to working with data (specific project only)

( ) Research tissue bank

( ) Research database

If your work does not fit any of these categories, select the option below:

( ) Other study

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation?	( ) Yes	(●) No
b) Will you be taking new human tissue samples (or other human biological samples)?	( ) Yes	(●) No
c) Will you be using existing human tissue samples (or other human biological samples)?	( ) Yes	(●) No

3. In which countries of the UK will the research sites be located?*(Tick all that apply)*

[x] England
[ ] Scotland

☐ Wales
☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

◉ England
◯ Scotland
◯ Wales
◯ Northern Ireland
◯ This study does not involve the NHS

4. Which applications do you require?

IMPORTANT: If your project is taking place in the NHS and is led from England select 'IRAS Form'. If your project is led from Northern Ireland, Scotland or Wales select 'NHS/HSC Research and Development Offices' and/or relevant Research Ethics Committee applications, as appropriate.

☑ IRAS Form
☐ Confidentiality Advisory Group (CAG)
☐ National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D Offices in Northern Ireland, Scotland and Wales the CI must create NHS/HSC Site Specific Information forms, for each site, in addition to the study wide forms, and transfer them to the PIs or local collaborators.

For participating NHS organisations in England different arrangements apply for the provision of site specific information. Refer to IRAS Help for more information.

Most research projects require review by a REC within the UK Health Departments' Research Ethics Service. Is your study exempt from REC review?

◯ Yes ◉ No

5. Will any research sites in this study be NHS organisations?

◉ Yes ◯ No

5a. Are all the research costs and infrastructure costs (funding for the support and facilities needed to carry out research e.g. NHS Support costs) for this study provided by a NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC), NIHR Patient Safety Translational Research Centre or a Diagnostic Evidence Co-operative in all study sites?

Please see information button for further details.

◯ Yes ◉ No

Please see information button for further details.

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) Support and inclusion in the NIHR Clinical Research Network Portfolio?

Please see information button for further details.

◯ Yes ◉ No

The NIHR Clinical Research Network provides researchers with the practical support they need to make clinical studies happen in the NHS e.g. by providing access to the people and facilities needed to carry out research "on the ground".

If you select yes to this question, you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form (PAF) immediately after completing this project filter question and before submitting other applications. Failing to complete the PAF ahead of other applications e.g. HRA Approval, may mean that you will be unable to access NIHR CRN Support for your study.

6. Do you plan to include any participants who are children?

○ Yes ◉ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

○ Yes ◉ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes ◉ No

9. Is the study or any part of it being undertaken as an educational project?

◉ Yes ○ No

Please describe briefly the involvement of the student(s):
The research project is being undertaken as part of a Doctorate in Clinical Psychology (DClinPsy) for Rebecca Mayor the Chief Investigator.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

◉ Yes ○ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

○ Yes ◉ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

○ Yes ◉ No

Integrated Research Application System
Application Form for Research administering questionnaires/interviews for quantitative analysis or mixed methodology study

IRAS Form (project information)

Please refer to the E-Submission and Checklist tabs for instructions on submitting this application.

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Please define any terms or acronyms that might not be familar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
Experiences of difficult emotions in people with seizures

Please complete these details after you have booked the REC application for review.

REC Name:
South West-Frenchay

REC Reference Number:
17/SW/0014

Submission date:
03/01/2017

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

An exploration of the experiences of difficult emotions in people with seizures

A2-1. Educational projects

Name and contact details of student(s):

Student 1

	Title	Forename/Initials	Surname
	Miss	Rebecca	Mayor
Address	Clinical Psychology		
	Division of Health Research, Furness College		
	Lancaster University, Lancaster		
Post Code	LA1 4YT		
E-mail	r.mayor@lancaster.ac.uk		
Telephone	01524 593301		
Fax			

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:

Doctorate in Clinical Psychology (DClinPSy)

Name of educational establishment:
Lancaster University

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
	Dr	Jane	Simpon
Address	Division of Health Research, Furness College		
	Lancaster University		
	Lancaster		
Post Code	LA1 4YT		
E-mail	j.simpson@lancaster.ac.uk		
Telephone			
Fax			

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	**Academic supervisor(s)**
Student 1 Miss Rebecca Mayor	☑ Dr Jane Simpon

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- (●) Student
- ( ) Academic supervisor
- ( ) Other

A3-1. Chief Investigator:

	Title	Forename/Initials	Surname
	Miss	Rebecca	Mayor
Post	Trainee Clinical Psychologist		
Qualifications	BSc		
ORCID ID			
Employer	Lancashire Social Care Trust		
Work Address	Clinical Psychology, Division of Health Research		
	Furness College, Lancaster University		
	Lancaster		
Post Code	LA1 4YT		
Work E-mail	r.mayor@lancaster.ac.uk		
* Personal E-mail			

Work Telephone

* Personal Telephone/Mobile

Fax

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and HRA/R&D reviewers that is sent to the CI.

	Title	Forename/Initials	Surname
	Ms	Diane	Hopkins
Address	Research Integrity and Governance Officer		
	Research Services Room B14, Furness College		
	Lancaster		
Post Code	LA1 4YT		
E-mail	d.hopkins@lancaster.ac.uk		
Telephone	01524 592838		
Fax			

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):

Sponsor's/protocol number:

Protocol Version:

Protocol Date:

Funder's reference number:

Project website:

Additional reference number(s):

Ref.Number Description	Reference Number

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

○ Yes ◉ No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments' Research Ethics Service, this summary will be published on the Health Research Authority (HRA) website following the ethical review. Please refer to the question specific guidance for this question.*

It has been evidenced that people with seizures are more likely to experience psychological distress and poor quality of life. This study aims to establish how people with epileptic seizures experience the emotion of self-disgust. The study will involve asking people with seizures to complete a measure of self-disgust and then interviewing approximately 12 participants to explore their experiences of this in more detail.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, HRA, or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

This study has been designed to expose participants to minimal risk. The interview schedule involves discussing emotions but should participants become distressed during the interview, the interview will be halted and participants will be given time to recover. Participants will be asked if they wish to continue and information about how to access further support may also be provided.
Participants will be provided with a Participant Information Sheet and an opportunity to ask the researcher any questions before giving their informed consent to participate in all phases of the study. They will be informed that they may withdraw this consent at any time without effect on their care.
They will be given time to consider the information sheet and decide whether they wish to take part.
Interviews will be held in participants homes or over the telephone. The Lancashire Care Foundation Lone Working policy will be followed to ensure the safety of the researcher. The interviews will be conducted by a trainee clinical psychologist who will be familiar with this particular patient group and working with people who might become distressed (Rebecca Mayor). While the interview will specifically focus on the topic of self-disgust it it possible that participants might talk about other negative emotions as well during the course of the interview and become distressed. If this were to happen the interview could be suspended. If appropriate the patient will be directed to other sources of support as detailed in the information sheet.
Participants will be made aware that should they disclose any information which gives the researcher cause for concern about the safety of the participant or another that this information may need to be shared. This will be discussed in supervision and appropriate bodies (such as safeguarding teams or the police) may be contacted if necessary.
All paper data will scanned and stored electronically and then destroyed as soon as possible (consent forms and questionnaires). Any paper data will be stored in a lockable filing cabinet with access only to the researcher in the meantime.
Interviews will be recorded using a digital recorder. For devices which are not encrypted, this data will be transferred to a computer and then deleted from the device as soon as possible. The interviews will be transcribed for qualitative analysis. All names will be replaced with pseudonyms during the transcription process and only anonymous quotes would be used in publications resulting from the qualitative analysis. All electronic data will be stored securely on the Lancaster University server. Files will be password protected as an additional security measure.
At the end of the study, all study data (consent forms, interview transcripts and any coded data produced during analysis) will be transferred electronically using a secure method that is supported by the University for long term storage on the
Lancaster University secure server. Consent forms will be scanned and stored electronically. Documents will be encrypted and password protected. Long term electronic storage of the encrypted and password protected data will be kept for 10 years by Lancaster University. Access will only be granted to the Lancaster University Research co-ordinator in case access is required to the data.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply*:

- ☐ Case series/ case note review
- ☐ Case control
- ☐ Cohort observation

- ☐ Controlled trial without randomisation
- ☐ Cross-sectional study
- ☐ Database analysis
- ☐ Epidemiology
- ☐ Feasibility/ pilot study
- ☐ Laboratory study
- ☐ Metanalysis
- ☑ Qualitative research
- ☑ Questionnaire, interview or observation study
- ☐ Randomised controlled trial
- ☐ Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

This study aims to establish whether people with seizures experience the emotion of self-disgust and what their experiences of this are.

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

Epilepsy is a group of neurological diseases characterised by the presence of epileptic seizures (Fisher et al., 2014). Epileptic seizures are short interruptions to the normal electrical functioning of the brain (Altrup, Elger & Reuber, 2009). There are several types of epileptic seizure which range from alterations in consciousness, to collapsing and shaking of the whole body.

High levels of psychological distress have been described in people who experience seizures, including people with a diagnosis of epilepsy (Beyenburg et al., 2005; Hoppe & Elger, 2011). It has been reported that the rates of people diagnosed with mood and anxiety disorders are two or three times higher in people with epilepsy than in the general population (Tellez-Zenteno et al., 2007) and that the number of people who report symptoms of depression may be as high as 50-55% in people with epilepsy (Boylan et al., 2004; Mendez et al., 1986). Experiencing seizures and psychological distress has been shown to have a negative impact on emotional, physical and social functioning and thus people with seizures often experience poorer quality of life, (Reuber, Pukrop, Mitchell, Bauer, & Elger, 2003; Verrotti et al 2014).
A number of qualitative studies have considered the impact of seizures on people's lives, including psychological and social functioning. Qualitative studies have reported epilepsy being associated with emotions including anger, frustration, low mood, embarrassment and worry (Kerr et al., 2011) as well as feelings of shame and guilt (Chung et al., 2012). People with seizures, have also reported feelings of shame, stigma, prejudice and embarrassment (Raty & Wilde-Larsson 2011).

One potential, yet under-researched, emotion relevant to the experience of seizures is disgust. Disgust is a universal human emotion (Ekman, 1999). A psychological model of disgust has been proposed which describes four categories of disgust elicitors and the functions (Rozin, Haidt, & McCauley, 2008). These include core elicitors such as food and body waste products (e.g., faeces, vomit, urine) which protect us from harm and disease; animal-nature elicitors such as sex, death and hygiene that protect our soul and mortality; interpersonal disgust such as through contact with contaminated others; and moral disgust elicited by moral violations which protect our social status.
The concept of disgust was for many years neglected in psychological research. More recently, however disgust has been increasingly investigated in a range of mental health conditions, including schizophrenia, obsessive-compulsive disorder and depression (Olatunji & McKay, 2007). The interest in discrete emotions, such as disgust, has also extended to health research (Consedine & Moscowitz, 2007).
However, research into self–disgust, disgust directed at oneself, is still in its infancy within psychology. Increased interest into self-disgust has led to identification of the emotion in other populations, including people with depression (Powell et al., 2013), eating disorders (Fox, 2009), and social anxiety (Amir, Najmi, Bomyea, & Burns, 2010). But the concept of self-disgust and its role in adaptation to physical health conditions is in its infancy. It has been suggested that self-disgust in physical health conditions might have both beneficial and detrimental effects on outcomes (Powell

et al., 2015) and there is therefore the potential for further exploration of this relationship.
Historically epilepsy has been associated with a range of misconceptions and myths (International League Against Epilepsy (ILAE), 2003). For example, a number of religions have considered those who experienced seizures as being possessed and that epilepsy was caused by an “unclean dumb and deaf spirit” (p. 12) or that people with epilepsy were contagious and infectious. The symptoms of seizures may therefore be relevant to all of the disgust categories described above. Individuals who experience seizures may potentially have to confront a range of disgust-inducing stimuli, including being sick or vomiting, bladder and bowel problems and being socially stigmatised.
Summary
The symptoms associated with seizures and the already recognised emotions and concerns reported by people seizures may therefore suggest that self-disgust may be worthy of investigation in this population. In those who report experiencing symptoms of self-disgust, a qualitative methodology will allow for a richer understanding of this currently unrecognised concept. Such research may help establish what emotions may be relevant for people who experience seizures and which psychological factors to consider during psychological therapeutic interventions in order to relieve distress and improve quality of life in these individuals. Using a qualitative methodology, the current study will therefore explore the experiences of self-disgust in people with seizures.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

Potential participants will be approached via two sources. Either by a member of their neurology care team or via an epilepsy charity (Epilepsy Action). Participants will be informed about a research study. They will receive an information sheet, consent form and a measure of self-disgust.
Participants will be allowed time to take this information away and consider the study. Those who wish to take part can complete the self-disgust questionnaire and consent form and return these to the researcher, either in paper form in the post or online. Participants will also have opportunities to speak to the researcher directly to discuss the research in more detail and ask questions. Participants will be made aware that a proportion of participants may be invited to further take part in an in-depth qualitative interview whilst others may not.
Those who are selected to take part in an interview will be contacted by the researcher to invite them to this. A convenient time and place to attend will be arranged. Alternatively, participants may choose to take part in a telephone interview.
Those who are not invited to attend for an interview will also be notified of this within 4 weeks.
Interviews will be audio recorded and transcribed verbatim. Interview transcripts will be analysed using Thematic Analysis to identify emerging themes in the data.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- ☐ Design of the research
- ☐ Management of the research
- ☑ Undertaking the research
- ☐ Analysis of results
- ☑ Dissemination of findings
- ☐ None of the above

Give details of involvement, or if none please justify the absence of involvement.
The research will be advertised by an epilepsy charity (Epilepsy Action) in order to approach eligible participants. People may share this if they choose.
A summary of the results of the study will be provided to participants if they choose which they will be welcome to share with others. A copy will also be sent to the charity involved in the recruitment of participants.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A15. What is the sample group or cohort to be studied in this research?

Select all that apply:

- [ ] Blood
- [ ] Cancer
- [ ] Cardiovascular
- [ ] Congenital Disorders
- [ ] Dementias and Neurodegenerative Diseases
- [ ] Diabetes
- [ ] Ear
- [ ] Eye
- [ ] Generic Health Relevance
- [ ] Infection
- [ ] Inflammatory and Immune System
- [ ] Injuries and Accidents
- [x] Mental Health
- [ ] Metabolic and Endocrine
- [ ] Musculoskeletal
- [x] Neurological
- [ ] Oral and Gastrointestinal
- [ ] Paediatrics
- [ ] Renal and Urogenital
- [ ] Reproductive Health and Childbirth
- [ ] Respiratory
- [ ] Skin
- [ ] Stroke

Gender:	Male and female participants
Lower age limit: 16	Years
Upper age limit:	No upper age limit

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

• Have received a clinical diagnosis of epilepsy from a neurologist
• Experienced an epileptic seizure in the last 12 months
• Are over the age of 16
• Are English speaking or able to complete a questionnaire and interview in English
• Are able to provide informed consent to take part in the study.

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

a) Communication or learning problems of sufficient severity to prevent from providing informed consent to take part in the study.
b) Communication or learning problems of sufficient severity to reduce participants' ability to take part in a semi-structured interview.
c) Non-English speakers

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Consent to Contact	1		2 minutes	Neurologists will inform patients about a research study. Those interested in hearing more about this can complete the form for their contact details to be passed to the researcher.
Demographic questionnaire	1		2 minutes	Participants will be asked to complete a short demographic questionnaire.
Self-disgust questionnaire (SDS)	1		15 minutes	Participants will be asked to complete the questionnaire at the time of recruitment to the study and asked to return this to the researcher, either in paper format or online.
Qualitative Interview	1		1 hour	Conducted by chief investigator in person or over phone with participant.

A21. How long do you expect each participant to be in the study in total?

Participants will be involved in the study for a short period. Some participants will not be invited to an interview following their completion of the recruitment materials and their input will end then. Participants invited to an interview will be expected to have completed this within one month. Participants who are not selected for interview will be notified about this with 4 weeks of providing consent.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

This study has been designed to expose patients to minimal risk. Altough the interview will involve talking about emotions, should participants become distressed during the interview, the interview will be halted and participants will be given time to recover. Participants will be asked if they wish to continue and information about how to access further support will be provided.
Participants will be provided with a Participant Information Sheet and an opportunity to ask the researcher any questions before giving their informed consent to participate in all phases of the study. They will be informed that they may withdraw this consent at any time without any effect on their care.
The interviews will be conducted by trainee clinical psychologist who will be familiar with this particular patient group (Rebecca Mayor).

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

◉ Yes ○ No

If Yes, please give details of procedures in place to deal with these issues:

Some participants could find talking about their condition and their emotions upsetting. However, participants will have had an opportunity to consider the nature of the project and speak to the researcher about this. Participants can choose whether or not they wish to take part in the research.
The researcher is familiar in with working with this patient group. Should patients become distressed they will be able to talk about this with the researcher and will be offered information on where they might access further support

should they require.
Participants will be made aware before they agree to take part in the study that should they share information which leads the researcher to worry about the safety of the participant or others that this information may need to be shared.

A24. What is the potential for benefit to research participants?

The research study may not be of direct benefit to participants themselves. However, we hope that the findings of this study will develop awareness of the psychological needs of people with epilepsy and inform future support.

A26. What are the potential risks for the researchers themselves? *(if any)*

There should be limited risk to the researchers themselves. Some interviews may take place in participants' home in which case the researcher will follow the Lancashire Care lone working policy.
A buddy system will be used in which a colleague will be fully notified of the movements of the Lone Worker. They will have all necessary contact details for the Lone Worker, including personal contact details, such as next of kin and details of vehicles used by the researcher, for example, registration number, make, model and colour.
The researcher will ensure regular contact with their colleague, particularly if they are delayed or have to cancel an appointment. If contact is not received at the agreed time, the buddy will attempt to contact the Lone Worker, and Where there is genuine concern, the buddy will follow the agreed local escalation procedures for alerting their Senior manager or the police.
In addition, the 'buddy' will be made aware that they have been nominated and what the procedures and requirement for this role are. Contingency arrangements will be in place for someone else to take over the role of the 'buddy' in case the nominated person is unable to carry out this role for any reason.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used?*For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

Potential participants will be approached via two sources.

1. Existing patients with epilepsy will be approached by a member of their neurology care team. They will be told about a research study. If they are interested in hearing more about the study they can agree to complete a contact form and their details will be passed to the researcher. They will be given a study pack (including information sheet, consent form and questionnaire). Participants will receive a phone call from the researcher at their stated preferred time to discuss the study. If participants wish to take part they can complete the study materials or complete these online if they wish.

2. The epilepsy charity, Epilepsy Action will advertise the research study. The invitation letter will be shared via their website and social media (including Facebook and Twitter). Participants will be invited to contact the researcher for further information about the study should they wish. A link to consent to take part in the study and complete the study materials online will be provided.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

○ Yes ◉ No

Please give details below:

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

◉ Yes ○ No

If Yes, please give details of how and where publicity will be conducted, and enclose copy of all advertising material (with version numbers and dates).

Epilepsy Action will share the recruitment letter via their website and social media.

A29. How and by whom will potential participants first be approached?

Existing patients will be approached by a member of their care team. They will be provided with paper versions of the study materials. Participants can consent to their details being passed to the researcher to receive a phone call giving more details about the study. Participants can complete these and return these to the researcher should they wish to take part.

Alternatively, participants may be made aware of the study via the Epilepsy charity's website or social media. Participants will be invited to access the study documents online. They will be able to click on a link which provides information about the study via the participant information sheet (PIS). Participants will be provided with contact details for the researcher should they wish to discuss the study. They will then be given a link to the consent form which will require them to provide consent via ticking the relevant boxes, following which they will be taken to the questionnaire.

A30-1. Will you obtain informed consent from or on behalf of research participants?

◉ Yes ○ No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

All participants will be provided with information about what their participation may involve. Participants will also be invited to contact the researcher directly should they wish to discuss the research in more detail. The researcher will explain more about the study and answer the participant's questions.
Potential participants will receive an information sheet, consent form and a measure of self-disgust. Those who wish to take part can complete the self-disgust questionnaire and consent form and return these to the researcher.
Participants will be made aware that a proportion of participants may be invited to further take part in an in-depth qualitative interview, whilst others may not.
Only participants able to provide informed consent will be included in the study.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

◉ Yes ○ No

A31. How long will you allow potential participants to decide whether or not to take part?

Participants will be recruited over a 3 month period after this period no more participants will be invited to take part in the study and the online materials will be removed. Participants will be given time to consider the information and ask the researcher questions should they wish. After completion of the study materials, participants will be expected to complete the interview within one month.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?*(e.g. translation, use of interpreters)*

Non-English speakers or those with communication or learning problems of sufficient severity to reduce patients' ability to take part in a semi-structured interview or provide informed consent will be excluded from the study.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

- ○ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- ○ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- ○ The participant would continue to be included in the study.
- ○ Not applicable – informed consent will not be sought from any participants in this research.
- ◉ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)?*(Tick as appropriate)*

- ☐ Access to medical records by those outside the direct healthcare team
- ☐ Access to social care records by those outside the direct social care team
- ☐ Electronic transfer by magnetic or optical media, email or computer networks
- ☐ Sharing of personal data with other organisations
- ☐ Export of personal data outside the EEA
- ☑ Use of personal addresses, postcodes, faxes, emails or telephone numbers
- ☑ Publication of direct quotations from respondents
- ☐ Publication of data that might allow identification of individuals
- ☑ Use of audio/visual recording devices
- ☑ Storage of personal data on any of the following:
  - ☐ Manual files (includes paper or film)
  - ☐ NHS computers
  - ☐ Social Care Service computers
  - ☐ Home or other personal computers
  - ☐ University computers
  - ☐ Private company computers
  - ☑ Laptop computers

Further details:
A participant log with participants' personal details, pseudonyms and contact information will be stored securely and separately from any other study data on a personal space on the Lancaster University server. This will be password protected for further security.

Interviews will be audio recorded. These recordings will be transferred to a personal space on the Lancaster University server via virtual private network as soon as possible and will be password protected for further protection. Any identifiable data (including recordings of participants' voices) will be deleted from the recorder as quickly as possible and in the meantime the recorder will be stored securely.
Audio files will be transcribed and the audio files will be deleted. All names will be replaced with pseudonyms during the transcription process and only anonymised quotes would be used in publications resulting from the qualitative analysis.
All electronic files will be stored on the Lancaster University secure server with access only from the CI.

A37. Please describe the physical security arrangements for storage of personal data during the study?

Manual files will be stored in a lockable filing cabinet with access only to the researcher during the study. Paper data will be scanned and stored electronically on a personal space on the Lancaster University server via virtual private network as soon as possible and will then be destroyed.

Interviews will be recorded using a digital recorder. For devices which are not encrypted, this data will be transferred to a computer and then deleted from the device as soon as possible. The interviews will be transcribed and stored electronically. All electronic data will be stored securely on the Lancaster University server. Files will be password protected as an additional security measure.

At the end of the study, all study data will be transferred electronically using a secure method that is supported by the University for long term storage on the
Lancaster University secure server. Documents will be encrypted and password protected. Long term electronic storage of the encrypted and password protected data will be kept for 10 years by Lancaster University. The data will then be destroyed by the Lancaster DClinPsy research co-ordinator after this time.

A38. How will you ensure the confidentiality of personal data?*Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

A participant log with participants personal details, pseudoynms and contact information will be stored securely on a personal space on the University server and separately from any other study data.
Transcripts of interviews will be made anonymous (only identifiable by allocated
participant pseudnyms).
Only anonymous data will be included for publication, using pseudnymns.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

Access to participants' personal data will only be granted to the research team.
[redacted] R&D require information about participants recruited from their sites as part of routine service accrual audit. Names of participants from this site and the date they consent to take part will therefore be shared with the research co-ordinator assigned from the R&D office. No other participant information will be shared with them.

Storage and use of data after the end of the study

A41. Where will the data generated by the study be analysed and by whom?

The study data will be analysed by the chief investigator. No personal data will be included, participants' names will be replaced by pseudonyms to ensure confidentiality. The transfer of any transcripts or analysed data will be anonymous and will be password protected as an additional security measure.

A42. Who will have control of and act as the custodian for the data generated by the study?

	Title	Forename/Initials	Surname
	Miss	Rebecca	Mayor
Post	Trainee Clinical Psychologist		

Qualifications	BSc
Work Address	Clinical Psychology
	Division of Health Research, Furness College
	Lancaster University, Lancaster
Post Code	LA1 4YT
Work Email	r.mayor@lancaster.ac.uk
Work Telephone	01524 593301
Fax	

A43. How long will personal data be stored or accessed after the study has ended?

- ○ Less than 3 months
- ○ 3 – 6 months
- ○ 6 – 12 months
- ○ 12 months – 3 years
- ◉ Over 3 years

If longer than 12 months, please justify:
At the end of the study data (including consent forms) will be transferred electronically using a secure method that is supported by the University for long term storage on the Lancaster University secure server. Documents will be encrypted and password protected. Long term electronic storage of the encrypted and password protected data will be kept for 10 years by Lancaster University. Access will only be granted to the Lancaster University DClinPsy admin team.

A44. For how long will you store research data generated by the study?

Years: 10
Months:

A45. Please give details of the long term arrangements for storage of research data after the study has ended.*Say where data will be stored, who will have access and the arrangements to ensure security.*

At the end of the study, data (interview transcripts and any coded data produced during analysis) will be transferred electronically using a secure method that is supported by the University for long term storage on the Lancaster University secure server. Documents will be encrypted and password protected. Long term electronic storage of the encrypted and password protected data will be kept for 10 years by Lancaster University. Access will only be granted to the Lancaster University DClinPsy admin team.

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

◉ Yes ○ No

If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined.
Participants will be granted travel expenses to interview up to £10.

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

○ Yes ◉ No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

○ Yes ◉ No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

○ Yes ◉ No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

○ Yes ○ No

Please give details, or justify if not registering the research.
The research may be registered on the local NHS trust databases involved in the study.

Registration of research studies is encouraged wherever possible.
You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study?*Tick as appropriate:*

☑ Peer reviewed scientific journals
☐ Internal report
☐ Conference presentation
☐ Publication on website
☐ Other publication
☐ Submission to regulatory authorities
☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
☐ No plans to report or disseminate the results
☑ Other (please specify)

The results of the study will be written and submitted to the University of Lancaster as part of a DClinPsy. This will also be modified for publication in a peerreviewed journal.
A summary report will also be available to participants should they request this as well as the epilepsy charity involved in recruitment.

A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when publishing the results?

Quotes from participant inteviews will be included in the write up of the study. All names will be placed by pseudonyms and no identifiable data will be included.

A53. Will you inform participants of the results?

(●) Yes ( ) No

Please give details of how you will inform participants or justify if not doing so.
A summary report will also be available to participants should they request this. This summary will also be sent to the charities involved in the study in order to disseminate this more widely.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed?*Tick as appropriate:*

- [ ] Independent external review
- [ ] Review within a company
- [ ] Review within a multi−centre research group
- [x] Review within the Chief Investigator's institution or host organisation
- [x] Review within the research team
- [x] Review by educational supervisor
- [ ] Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:
The study proposal has been reviewed by the research team, including the academic supervisor. This has also been reviewed by the Lancaster University research office .

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A56. How have the statistical aspects of the research been reviewed?*Tick as appropriate:*

- [ ] Review by independent statistician commissioned by funder or sponsor
- [ ] Other review by independent statistician
- [ ] Review by company statistician
- [ ] Review by a statistician within the Chief Investigator's institution
- [ ] Review by a statistician within the research team or multi−centre group
- [ ] Review by educational supervisor
- [ ] Other review by individual with relevant statistical expertise
- [x] No review necessary as only frequencies and associations will be assessed – details of statistical input not required

In all cases please give details below of the individual responsible for reviewing the statistical aspects. If advice has been provided in confidence, give details of the department and institution concerned.

Title Forename/Initials Surname

Department
Institution
Work Address

Post Code
Telephone
Fax
Mobile
E-mail

Please enclose a copy of any available comments or reports from a statistician.

A57. What is the primary outcome measure for the study?

The study uses qualitative methodology. The outcome of the study is therefore the quotes from participants detailing their experiences.

A58. What are the secondary outcome measures?*(if any)*

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size: 12
Total international sample size (including UK):
Total in European Economic Area:

Further details:
Up to 12 participants will be interviewed.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

A sample size calculation was not completed as this is a qualitative study. The data will analysed with Thematic Aanalysis and a study size of 12 should be adequate to ensure that adequate themes are identified.

A61. Will participants be allocated to groups at random?

○ Yes ◉ No

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

Interviews will be recorded and transcribed verbatim. The data will be analysed using Thematic Analysis. Based on the Braun and Clark (2006) model, the data will be analysed to identify, analyse and report patterns (themes) within the data that are associated with the research question.
This model of qualitative analysis involves 6 phases: 1. Familiarising with the data. 2. Generating initial codes. 3. Searching for themes. 4. Reviewing Themes. 5. Defining and naming themes. 6. Producing the report.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co−applicants, protocol co−authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title	Forename/Initials	Surname
	[redacted]	[redacted]	[redacted]uber
Post	[redacted]		
Qualifications	[redacted]		
Employer	[redacted]		
Work Address	[redacted]		
	[redacted]		
Post Code	[redacted]		
Telephone	[redacted]		
Fax			
Mobile			
Work Email	[redacted]		

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

Status:
- ○ NHS or HSC care organisation
- ◉ Academic
- ○ Pharmaceutical industry
- ○ Medical device industry
- ○ Local Authority
- ○ Other social care provider (including voluntary sector or private organisation)
- ○ Other

Commercial status:

If Other, please specify:

Contact person

Name of organisation	Lancaster University
Given name	Diane
Family name	Hopkins
Address	B14 Furness, Lancaster University
Town/city	Lancaster
Post code	LA1 4YT
Country	UNITED KINGDOM
Telephone	+44 (0) 1524 592838
Fax	
E-mail	d.hopkins@lancaster.ac.uk

Is the sponsor based outside the UK?

○ Yes ◉ No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?

- ☐ Funding secured from one or more funders
- ☐ External funding application to one or more funders in progress
- ☑ No application for external funding will be made

What type of research project is this?

- ○ Standalone project
- ○ Project that is part of a programme grant
- ○ Project that is part of a Centre grant
- ○ Project that is part of a fellowship/ personal award/ research training award
- ○ Other

Other – please state:

A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1) ? *Please give details of subcontractors if applicable.*

○ Yes ○ No

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

○ Yes ◉ No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

	Title	Forename/Initials	Surname
	[redacted]	[redacted]	[redacted]
Organisation	[redacted]		
Address	[redacted]		
	[redacted]		
	[redacted]		
Post Code	[redacted]		
Work Email	[redacted]		
Telephone	[redacted]		
Fax			
Mobile			

Details can be obtained from the NHS R&D Forum website: http://www.rdforum.nhs.uk

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/12/2016
Planned end date: 31/05/2017
Total duration:
Years: 0 Months: 5 Days: 31

A71-1. Is this study?

- (●) Single centre
- ( ) Multicentre

A71-2. Where will the research take place? *(Tick as appropriate)*

- [x] England
- [ ] Scotland
- [ ] Wales
- [ ] Northern Ireland
- [ ] Other countries in European Economic Area

Total UK sites in study 1

Does this trial involve countries outside the EU?
( ) Yes ( ) No

A72. Which organisations in the UK will host the research?*Please indicate the type of organisation by ticking the box and give approximate numbers if known:*

- [x] NHS organisations in England 1
- [ ] NHS organisations in Wales
- [ ] NHS organisations in Scotland
- [ ] HSC organisations in Northern Ireland
- [ ] GP practices in England
- [ ] GP practices in Wales
- [ ] GP practices in Scotland
- [ ] GP practices in Northern Ireland
- [ ] Joint health and social care agencies (eg community mental health teams)
- [ ] Local authorities
- [ ] Phase 1 trial units
- [ ] Prison establishments
- [ ] Probation areas
- [ ] Independent (private or voluntary sector) organisations
- [ ] Educational establishments
- [ ] Independent research units
- [ ] Other (give details)

Total UK sites in study: 1

A73-1. Will potential participants be identified through any organisations other than the research sites listed above?

(●) Yes ( ) No

A73-2. If yes, will any of these organisations be NHS organisations?

( ) Yes (●) No

If yes, details should be given in Part C.

A74. What arrangements are in place for monitoring and auditing the conduct of the research?

The chief investigator will engage in regular supervision meetings with the academic supervisor and other members of the research team to ensure appropriate management of the study data.

A76. Insurance/ indemnity to meet potential legal liabilities

***Note:* in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland**

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? *Please tick box(es) as applicable.*

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (NHS sponsors only)

☑ Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply.

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? *Please tick box(es) as applicable.*

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)

☑ Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply.

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

☑ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)

☐ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Please enclose a copy of relevant documents.

A78. Could the research lead to the development of a new product/process or the generation of intellectual property?

○ Yes ◉ No ○ Not sure

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. *For further information please refer to guidance.*

Investigator identifier	Research site	Investigator Name
IN1	(●) NHS site ( ) Non-NHS site Country: England Organisation name [redacted] Address [redacted] Post Code [redacted]	Forename [redacted] Middle name Family name [redacted] Email [redacted] Qualification [redacted] Country [redacted]

PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.

2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.

3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.

4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.

5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.

6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.

7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.

8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.

9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:

    - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
    - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
    - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
    - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
    - May be sent by email to REC members.

10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.

11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication*(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

◯ Chief Investigator

- ◯ Sponsor
- ◯ Study co-ordinator
- ◯ Student
- ◯ Other – please give details
- ◯ None

Access to application for training purposes *(Not applicable for R&D Forms)*

Optional – please tick as appropriate:

☐ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Miss Rebecca Mayor on 14/12/2016 16:10.

Job Title/Post:	Trainee Clinical Psychologist
Organisation:	Lancaster University
Email:	r.mayor@lancaster.ac.uk

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co−sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.

2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.

3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.

4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.

5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.

6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

   Please note: *The declarations below do not form part of the application for approval above. They will not be considered by the Research Ethics Committee.*

7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

8. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publically accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

This section was signed electronically by An authorised approver at ethics@lancaster.ac.uk on 03/01/2017 14:45.

Job Title/Post:	Research Support and Systems Manager
Organisation:	Lancaster University
Email:	b.gordon@lancaster.ac.uk

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.

2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

This section was signed electronically by jane simpson on 14/12/2016 16:51.

Job Title/Post:	Director of education
Organisation:	Lancaster university
Email:	J.simpson2@lancaster.ac.uk

Appendix 4-A. Protocol

PROJECT PROTOCOL

TITLE OF PROJECT

An exploration of the experiences of difficult emotions in people with seizures

Short title: Experiences of difficult emotions in people with seizures

RESEARCHERS INVOLVED

Lead applicant
Rebecca Mayor (Principal Investigator)
Trainee Clinical Psychologist
Division of Health Research, Furness College
Lancaster University LA1 4YT
R.Mayor@lancaster.ac.uk

Co-applicants

[redacted]

Jane Simpson
Director of Education, Division of Health Research
Lancaster University, Lancaster
J.simpson2@lancaster.ac.uk

SPONSOR

Lancaster University

CLINICAL AND SCIENTIFIC JUSTIFICATION

Seizures

Epilepsy is a group of neurological diseases characterised by the presence of epileptic seizures (Fisher et al., 2014). Epileptic seizures are short interruptions to the normal electrical functioning of the brain (Altrup, Elger & Reuber, 2009). There are several types of epileptic seizure which range from alterations in consciousness, to collapsing and shaking of the whole body.

Difficulties of seizure experiences

High levels of psychological distress have been described in people who experience seizures, including people with a diagnosis of epilepsy (Beyenburg et al., 2005; Hoppe & Elger, 2011). It has been reported that the rates of people diagnosed with mood and anxiety disorders are two or three times higher in people with epilepsy than in the general population (Tellez-Zenteno et al., 2007) and that the number of people who report symptoms of depression may be as high as 50-55% in people with epilepsy (Boylan et al., 2004; Mendez et al., 1986). Experiencing seizures and psychological distress has been shown to have a negative impact on emotional, physical and social functioning and thus people with seizures

often experience poorer quality of life, (Reuber, Pukrop, Mitchell, Bauer, & Elger, 2003; Verrotti et al 2014).

A number of qualitative studies have considered the impact of seizures on people's lives, including psychological and social functioning. One qualitative study looking at the impact of epilepsy and associated cognitive difficulties reported themes of living with the condition as affecting the whole of the person, impacting on a variety of factors including self-esteem and relationships (Gauffin et al., 2011). Other qualitative studies have reported epilepsy being associated with emotions including anger, frustration, low mood, embarrassment and worry (Kerr et al., 2011) as well as feelings of shame and guilt (Chung et al., 2012 People with epilepsy are known to be more avoidant of social situations (Kilinc & Campbell, 2009). People with seizures, have also reported feelings of shame, stigma, prejudice and embarrassment (Raty, & Wilde-Larsson, 2011).

Disgust and Self-Disgust

One potential, yet under-researched, emotion relevant to the experience of seizures is disgust. Disgust is a universal human emotion (Ekman, 1999). A psychological model of disgust has been proposed which describes four categories of disgust elicitors and the functions (Rozin, Haidt, & McCauley, 2008). These include core elicitors such as food and body waste products (e.g., faeces, vomit, urine) which protect us from harm and disease; animal-nature elicitors such as sex, death and hygiene that protect our soul and mortality; interpersonal disgust such as through contact with contaminated others; and moral disgust elicited by moral violations which protect our social status.

The concept of disgust was for many years neglected in psychological research., More recently, however disgust has been increasingly investigated in a range of mental health conditions, including schizophrenia, obsessive-compulsive disorder and depression (Olatunji & McKay, 2007). The interest in discrete emotions, such as disgust, has also extended to health research (Consedine & Moscowitz, 2007).

However, research into self–disgust, disgust directed at oneself, is still in its infancy within psychology. Self-disgust has been described as a "harsher" version of shame but distinct from low self-esteem (Simpson et al, 2010) and more recently, self-disgust has been proposed as a distinct emotional schema, involving both disgust-based feelings and cognitive elements. Self-disgust has been found to correlate with disgust, through high concurrent validity recorded between the Self-Disgust Scale (Overton, Markland, Taggart, Bagshaw, & Simpson, 2008) and the Disgust Sensitivity Scale (Haidt, McCauley, & Rozin, 1994).

Increased interest into self-disgust has led to identification of the emotion in other populations, including people with depression (Powell et al., 2013), eating disorders (Fox, 2009), and social anxiety (Amir, Najmi, Bomyea, & Burns, 2010). But the concept of self-disgust and its role in adaptation to physical health conditions is in its infancy. It has been suggested that self-disgust in physical health conditions might have both beneficial and detrimental effects on outcomes (Powell et al., 2015) and there is therefore the potential for further exploration of this relationship.

Historically epilepsy has been associated with a range of misconceptions and myths (International League Against Epilepsy (ILAE), 2003). For example, a number of religions have considered those who experienced seizures as being possessed and that epilepsy was

caused by an “unclean dumb and deaf spirit” (p. 12) or that people with epilepsy were contagious and infectious. The symptoms of seizures may therefore be relevant to all of the disgust categories described above. Individuals who experience epileptic seizures may potentially have to confront a range of disgust-inducing stimuli, including, being perceived as contaminating, being sick or vomiting, bladder and bowel problems and being socially stigmatised.

Summary

The symptoms associated with seizures and the already recognised emotions and concerns reported by people seizures may therefore suggest that self-disgust may be worthy of investigation in this population. In those who report experiencing symptoms of self-disgust, a qualitative methodology will allow for a richer understanding of this currently unrecognised concept. Such research may help establish what emotions may be relevant for people who experience seizures and which psychological factors to consider during psychological therapeutic interventions in order to relieve distress and improve quality of life in these individuals. Using a qualitative methodology, the current study will therefore aim to consider whether people with seizures experience self-disgust and if so, what their experiences of this are.

METHODS

DESIGN

Semi-structured qualitative interviews will be conducted with up to 12 participants. This should allow for a sufficient number of participants in order to address the research question using the methodology used and is in line with published research projects in this population using a similar research methodology (O’Toole, Lambert, Gallagher, Shahwan, & Austin, 2016).

Participants in this study will be recruited by a researcher from Lancaster University. Interviews will be held in a location of the participant’s choosing or over the phone.

PARTICIPANTS

i) Identification of participants

Participants will be identified through two sources. Either by a member of the Neurology care team in one of the participating centres or through an epilepsy charity.

ii) Inclusion Criteria

a) Participants must have received a clinical diagnosis of epilepsy from a neurologist.

b) Participants must have experienced an epileptic seizure within the past 12 months

c) Participants must be over the age of 16.

iii) Exclusion Criteria

a) Communication or learning problems of sufficient severity to prevent from providing informed consent to take part in the study.

b) Communication or learning problems of sufficient severity to reduce participants' ability to take part in a semi-structured interview.

c) Non-English speakers

MEASURES

In order to identify people who experience seizures and who have also experienced feelings of self-disgust, people who experience epileptic seizures will be asked to complete a self-rated measure of self-disgust, the Self Disgust Rating Scale (SDS, Powell, Simpson, & Overton, 2015).

PROCEDURE

Potential participants will be approached via two sources - either by a member of their neurology care team or through an epilepsy charity.

Participants attending neurology clinics will be informed about a research study. If they are interested, they will be provided with a study pack (containing an information sheet, consent form and a measure of self-disgust). Participants will be asked whether they agree to be contacted by the researcher to discuss the research in more detail and an opportunity to ask any questions. The neurologist will ask participants to complete the 'Consent to Contact' form. At this stage participants are only agreeing to be contacted by the researcher to hear more about the study.

The researcher will then contact participants at their stated preferred time of day. They will explain more about the study and answer the participant's questions. Participants can then choose whether they would like to take part in the study. They can complete the study pack (consent form and questionnaire) provided by the neurologist and return these to the researcher or can complete these online.

Those recruited through the epilepsy charity will be informed about the research study. They will be directed towards a weblink which will provide further information about the study and contact details for the researcher should they wish to hear more about the study. The researcher will explain more about the study and answer the participant's questions. Those who wish to take part can complete the self-disgust questionnaire and consent form.

All participants will be made aware that a proportion of participants may be invited to further take part in an in-depth qualitative interview.

Participants will be asked to provide contact detail at the time of consent so that the those who are selected to take part in an interview can be contacted by the researcher to invite them to this. Participants who score highly on the SDS will be invited to attend for an in depth interview with the researcher. A convenient time and place to attend will be arranged. Alternatively, participants may choose to take part in a telephone interview.

DATA ANALYSIS

Interviews will be recorded and transcribed verbatim. The data will be analysed using Thematic Analysis. Thematic analysis is a frequently used method of qualitative analysis within psychology (Braun & Clarke, 2006). It allows for themes to be directly identified from the data (Fereday & Muir-Cochrane, 2008) and for patterns of data referring to particular phenomena and relevant to a specific research question to be summarised (Daly, Kellehear, & Gliksman, 1997). Thematic analysis is therefore a useful method of data analysis when

exploring people's experiences of novel phenomenon. Thematic analysis was therefore chosen as the most appropriate methodology for the current study.

Based on the Braun and Clark (2006) model, the data will be analysed to identify, analyse and report patterns (themes) within the data that are associated with the research question. This model of qualitative analysis involves 6 phases: 1. Familiarising with the data. 2. Generating initial codes. 3. Searching for themes. 4. Reviewing Themes. 5. Defining and naming themes. 6. Producing the report. As part of this model a reflexive journal will also be kept to track reflections of interviews and analysis which will be incorporated in to the final reporting of the study.

PRACTICAL ISSUES

PROJECT MANAGEMENT

The research will be conducted as a basis for a postgraduate degree (DCinPsy) for Rebecca Mayor (Lancaster University) under the supervision of Dr Jane Simpson (Lancaster University) and [redacted]).

PROJECT PLAN

The study will be carried out over 10 months.
Months 1-3: Ethics and Research Governance approval
Months 4-6: Recruitment of participants.
Months 5-7: Transcription and data analysis
Months 8-9: Write-up

EXPERTISE OF RESEARCH TEAM

[redacted] has many years of clinical experience with this patient group and has conducted and published a large number of studies in this area, including DClinPsy projects. Rebecca Mayor has conducted multiple studies within this patient group in the last few years and is familiar with qualitative research. Dr Jane Simpson is experienced in supervising DClinPsy thesis projects, has published a large number of studies in psychological research and has particular interests in the subject area of self-disgust.

ETHICAL CONSIDERATIONS

<u>Risk to participants</u>

This study has been designed to expose participants to minimal risk. The measure of self-disgust may lead participants to think about difficult emotions, however, information will be provided on where they might access further support for this. The interview schedule has been designed to minimise the potential for distress in participants. Should participants become distressed during the interview, the interview will be halted and participants will be given time to recover. Participants will be asked if they wish to continue and information about how to access further support will be provided.

The interviews will be conducted by an experienced researcher who will be familiar with this particular patient group (Rebecca Mayor). The researcher is a Trainee Clinical Psychologist who is experienced in working with people who are distressed.

Consent

Participants recruited by their neurologist will be asked to complete a 'Consent to Contact' form agreeing to be contacted by the researcher to hear more about the study. They are only agreeing to hear more about the study at this stage.

Participants will be provided with a Participant Information Sheet, consent form and questionnaire. After speaking to the researcher, if they choose to take part in the research they can return the consent form and questionnaire to the researcher or do this online. Online participants will be asked to complete the consent form and questionnaire online.

All participants will have the researcher's contact details should they wish to discuss the study or ask questions before giving their informed consent to participate in the study. They will be informed that they may withdraw this consent at any time without any effect on their care. Only participants who are able to provide informed consent will be included in the study.

Data Storage

All paper data will be stored in a lockable filing cabinet with access only to the researcher. Electronic data will be stored securely on a personal space on the Lancaster University server via virtual private network. Files will be password-protected as an additional security measure. Interviews will be audio recorded using a digital recorder. All data will be transferred to a personal space on the Lancaster University server via virtual private network and then deleted from the device as soon as possible following transcription.

All identifiable information will be kept separately from self-report and interview data. Participants will be allocated a participant number and self-report forms will only be identifiable by this number. The interviews will be transcribed for qualitative analysis. All names will be replaced with pseudonyms during the transcription process and only anonymised quotes would be used in publications resulting from the qualitative analysis.

At the end of the study data (consent forms, interview transcripts and any coded data produced during analysis) will be transferred electronically using a secure method that is supported by the University for long term storage on the Lancaster University secure server. Documents will be encrypted and password protected. Long term electronic storage of the encrypted and password protected data will be kept for 10 years by Lancaster University. Access will only be granted to the Lancaster University DClinPsy admin team.

DISSEMINATION OF RESULTS

The write-up of this project will be submitted towards a postgraduate degree (DClinPsy) for Rebecca Mayor. It is hoped that the results of this study will be submitted for publication in a peer reviewed scientific journal to improve dissemination to the wider public. Participants will also be invited to receive a summary of the results of the study if they wish.

COSTING AND FUNDING

This study is supported by Lancaster University. Participants will be offered travel expenses for attending interviews. Stationary and postage costs will also be supported.

REFERENCES

Altrup, U., Elger, C. E., Reuber, M. (2009). Epilepsy Explained: A book for people who want to know more about epilepsy. New York: Oxford University Press,

Amir, N., Najmi, S., Bomyea, J., & Burns, M. (2010). Disgust and anger in social anxiety. International Journal Of Cognitive Therapy,3(1), 3-10. doi:10.1521/ijct.2010.3.1.3

Beyenburg S., Mitchell A. J., Schmidt D., Elger C. E., & Reuber, M. (2005). Anxiety in patients with epilepsy: Systematic review and suggestions for clinical management. Epilepsy & Behavior, 7, 161–171. doi:10.1016/j.yebeh.2005.05.014

Boylan, L. S., Flint, L. A., Labovitz, D. L., Jackson, S. C., Starner, K., & Devinsky, O. (2004). Depression but not seizure frequency predicts quality of life in treatment-resistant epilepsy. Neurology, 62(2), 258-261.

Consedine, N. S., & Moskowitz, J. (2007). The role of discrete emotions in health: A critical review. Applied and Preventive Psychology, 12, 59–75.

Chung, K., Liu, Y., Ivey, S. L., Huang, D., Chung, C., Guo, W., & ... Ma, D. (2012). Quality of life in epilepsy (QOLIE): Insights about epilepsy and support groups from people with epilepsy (San Francisco Bay Area, USA). Epilepsy & Behavior, 24(2), 256-263. doi:10.1016/j.yebeh.2012.02.003

Fisher, Robert S; Acevedo, C; Arzimanoglou, A; Bogacz, A; Cross, JH; Elger, CE; Engel J, Jr; Forsgren, L; French, JA; Glynn, M; Hesdorffer, DC; Lee, BI; Mathern, GW; Moshé, SL; Perucca, E; Scheffer, IE; Tomson, T; Watanabe, M; Wiebe, S (2014). ILAE Official Report: A practical clinical definition of epilepsy. *Epilepsia. 55(4),* 475–82. doi:10.1111/epi.12550

Gauffin, H., Flensner, G., & Landtblom, A. (2011). Living with epilepsy accompanied by cognitive difficulties: Young adults' experiences. Epilepsy & Behavior, 22(4), 750-758. doi:10.1016/j.yebeh.2011.09.007

Haidt, J., McCauley, C., & Rozin, P. (1994). Individual differences in sensitivity to disgust: A scale sampling seven domains of disgust elicitors. Personality and Individual Differences, 16(5), 701-713. doi:10.1016/0191-8869(94)90212-7.

Hoppe C., & Elger C.,E. (2011). Depression in epilepsy: a critical review from a clinical perspective. Nat Rev Neurol, 7(8), 462-72. doi: 10.1038/nrneurol.2011.104.

Kerr, C., Nixon, A., & Angalakuditi, M. (2011). The impact of epilepsy on children and adult patients' lives: Development of a conceptual model from qualitative literature. Seizure, 20(10), 764-774. doi:10.1016/j.seizure.2011.07.007

Kilinc S, & Campbell C. (2009). It shouldn't be something that's evil, it should be talked about: a phenomenological approach to epilepsy and stigma. Seizure, 18:,665–671. doi: 10.1016/j.seizure.2009.09.001

Mendez, M. F., Cummings, J. L., & Benson, F. (1986). Depression in epilepsy: Significance and phenomenology. Archives Of Neurology, 43(8), 766-770. doi:10.1001/archneur.1986.00520080014012

Olatunji, B. O., & Mckay, D. (2007). Disgust and psychiatric illness: Have we remembered? British Journal of Psychiatry, 190, 457–459. doi:10.1192/bjp.bp.106.032631

O'Toole, S., Lambert, V., Gallagher, P., Shahwan, A., & Austin, J. K. (2016). "I don't like talking about it because that's not who I am": Challenges children face during epilepsy-related family communication. Chronic illness, 1742395316644307.

Overton, P. G., Markland, F. E., Taggart, H. S., Bagshaw, G. L., & Simpson, J. (2008). Selfdisgust mediates the relationship between dysfunctional cognitions and depressive symptomatology. Emotion, 8(3), 379-385. doi:10.1037/1528-3542.8.3.379

Powell, P. A., Overton, P. G., & Simpson, J. (2014). The revolting self: An interpretative phenomenological analysis of the experience of self-disgust in females with depressive symptoms. Journal Of Clinical Psychology, 70(6), 562-578. doi:10.1002/jclp.22049

Powell, P. A., Overton, P. G., & Simpson, J. (2015). The revolting self: Perspectives on the psychological, social, and clinical implications of self-directed disgust. London, England: Karnac Books.

Räty, L. A., & Wilde-Larsson, B. M. (2011). Patients' perceptions of living with epilepsy: A phenomenographic study. Journal Of Clinical Nursing, 20(13-14), 1993-2002. doi:10.1111/j.1365-2702.2010.03572.x

Simpson, J., Hillman, R., Crawford, T., & Overton, P. G. (2010). Self-esteem and self-disgust both mediate the relationship between dysfunctional cognitions and depressive symptoms. Motivation And Emotion, 34(4), 399-406. doi:10.1007/s11031-010-9189-2

Tellez-Zenteno, J.F., Patten, S. B., Jette, N., Williams, J., & Wiebe, S. (2007) Psychiatric comorbidity in epilepsy: a population-based analysis. Epilepsia, 48, 2336–2344

Verrotti, A., Carrozzino, D., Milioni, M., Minna, M., & Fulcheri, M. (2014). Epilepsy and its main psychiatric comorbidities in adults and children. Journal Of The Neurological Sciences, 343(1-2), 23-29. doi:10.1016/j.jns.2014.05.043

Appendix 4-B. REC Approval

Health Research Authority
North West - Greater Manchester West Research Ethics Committee
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0207 104 8021

24 March 2017

Miss Rebecca Mayor
Trainee Clinical Psychologist
Lancashire Social Care Trust
Clinical Psychology, Division of Health Research
Furness College, Lancaster University
Lancaster
LA1 4YT

Dear Miss Mayor

Study title: **An exploration of the experiences of difficult emotions in people with seizures**
REC reference: **17/NW/0088**
IRAS project ID: **211769**

Thank you for your submission. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 13 February 2017

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Covering letter on headed paper [Response]		20 February 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnities]		01 August 2016
Interview schedules or topic guides for participants [Interview Guide]	2	14 December 2016
Letter from sponsor [Sponsor Letter]		03 January 2017
Letters of invitation to participant [Invite/ Consent to contact]	v2	14 December 2016
Other [Debrief]	1	16 February 2017
Participant consent form [Consent NHS/Online]	2	16 February 2017
Participant information sheet (PIS) [PIS NHS/Online]	3	16 February 2017
Validated questionnaire [Demographic/SDRS]	2	14 December 2016

Approved documents

The final list of approved documentation for the study is therefore as follows:

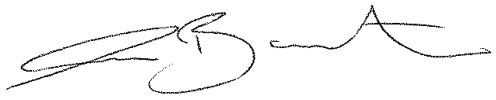
Document	*Version*	*Date*
Covering letter on headed paper [Response]		20 February 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		01 August 2016

Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnities]		01 August 2016
Interview schedules or topic guides for participants [Interview Guide]	2	14 December 2016
IRAS Application Form [IRAS_Form_03012017]		03 January 2017
IRAS Checklist XML [Checklist_03012017]		03 January 2017
Letter from sponsor		03 January 2017
Letter from sponsor [Sponsor Letter]		03 January 2017
Letters of invitation to participant [Invite/ Consent to contact]	v2	14 December 2016
Other [Debrief]	1	16 February 2017
Participant consent form [Consent NHS/Online]	2	16 February 2017
Participant information sheet (PIS) [PIS NHS/Online]	3	16 February 2017
Referee's report or other scientific critique report [Peer review]		23 February 2016
Research protocol or project proposal [Protocol]	2	14 December 2016
Summary CV for Chief Investigator (CI)		
Summary CV for supervisor (student research)		
Validated questionnaire [Demographic/SDRS]	2	14 December 2016

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

17/NW/0088 **Please quote this number on all correspondence**

Yours sincerely



Anna Bannister
REC Manager

E-mail: nrescommittee.northwest-gmwest@nhs.net

Copy to: *Ms Diane Hopkins*

[redacted]

Health Research Authority

Miss Rebecca Mayor
Trainee Clinical Psychologist
Lancashire Social Care Trust
Clinical Psychology, Division of Health Research
Furness College, Lancaster University
Lancaster
LA1 4YT

Email: hra.approval@nhs.net

07 April 2017

Dear Miss Mayor

Letter of HRA Approval

Study title:	**An exploration of the experiences of difficult emotions in people with seizures**
IRAS project ID:	**211769**
REC reference:	**17/NW/0088**
Sponsor	**Lancaster University**

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

Participation of NHS Organisations in England

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

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

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

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

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

Appendices

The HRA Approval letter contains the following appendices:

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

After HRA Approval

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

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

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

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

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

Scope

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

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

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

User Feedback

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

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

HRA Training

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

Your IRAS project ID is **211769**. Please quote this on all correspondence.

Yours sincerely

Beverley Mashegede
Assessor

Email: hra.approval@nhs.net

Copy to: Ms Diane Hopkins, Sponsor Contact

[redacted]

IRAS project ID	211769

Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	*Version*	*Date*
Contract/Study Agreement [SoA/SoE exemption]		29 November 2016
Covering letter on headed paper [Response]		20 February 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		01 August 2016
Interview schedules or topic guides for participants [Interview Guide]	2	14 December 2016
IRAS Application Form [IRAS_Form_03012017]		03 January 2017
IRAS Application Form XML file [IRAS_Form_03012017]		03 January 2017
IRAS Checklist XML [Checklist_03032017]		03 March 2017
Letter from sponsor [Sponsor Letter]		03 January 2017
Letters of invitation to participant [Invite/ Consent to contact]	v2	14 December 2016
Other [Debrief]	1	16 February 2017
Participant consent form [NHS/Online]	3	05 April 2017
Participant information sheet (PIS) [NHS/Online]	4	05 April 2017
Research protocol or project proposal [Protocol]	2	14 December 2016
Summary CV for Chief Investigator (CI)		
Summary CV for supervisor (student research)		
Validated questionnaire [Demographic/SDRS]	2	14 December 2016

IRAS project ID	211769

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations*, *capacity and capability* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Diane Hopkins
Tel: 01524 592838
Email: d.hopkins@lancaster.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	HRA Approval will only cover research activities at the NHS organisation.
2.1	Participant information/consent documents and consent process	Yes	The participant information sheet and consent form have been updated to bring them in line with HRA Approval standards via a minor amendment.
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The participating Trust has confirmed that they do not require a Statement of Activities and Schedule of Events to be completed for this study.
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this

Section	HRA Assessment Criteria	Compliant with Standards	Comments
			research study.
4.3	Financial arrangements assessed	Yes	No application for external funding made. No funds will be provided to the participating organisation to support this study.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	Favourable Opinion with conditions issued 13 February 2017. Favourable Opinion with conditions met issued 24 March 2017
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

IRAS project ID	211769

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.
This is a non-commercial student (Doctorate in Clinical Psychology (DClinPsy)) and there is one site type. The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website. If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.
The HRA has determined that participating NHS organisations in England **are not expected to formally confirm their capacity and capability to host this research.** • The HRA has informed the relevant research management offices that you intend to undertake the research at their organisation. However, you should still support and liaise with these organisations as necessary. • Following issue of the Letter of HRA Approval the sponsor may commence the study at these organisations when it is ready to do so. • The document "Collaborative working between sponsors and NHS organisations in England for HRA Approval studies, where no formal confirmation of capacity and capability is expected" provides further information for the sponsor and NHS organisations on working with NHS organisations in England where no formal confirmation of capacity and capability is expected, and the processes involved in adding new organisations. Further study specific details are provided the *Participating NHS Organisations* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections of this Appendix.

IRAS project ID	211769

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).
No PI or LC is expected at the participating organisation. GCP training is not a generic training expectation, in line with the HRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken
Where arrangements are not already in place, network staff (or similar) undertaking any research activities that may impact on the quality of care of the participant, would be expected to obtain an honorary research contract from one NHS organisation (if university employed), followed by Letters of Access for subsequent organisations. This would be on the basis of a Research Passport (if university employed) or an NHS to NHS confirmation of pre-engagement checks letter (if NHS employed). These should confirm enhanced DBS checks, including appropriate barred list checks, and occupational health clearance. For research team members undertaking activities that do not impact on the quality of care of the participant (for example, administering questionnaires), a Letter of Access based on standard DBS checks and occupational health clearance would be appropriate.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix 4-D. Participant Information Sheet

Participant Information Sheet

Research Study Title: Experiences of difficult emotions in people with seizures

I and my colleagues at Lancaster University and the [redacted] are conducting a new research study. This study will be part of my Doctorate in Clinical Psychology.

We would like to invite you to take part in the research study we are currently conducting into the experiences of certain emotions in people who experience seizures. Before you decide whether to take part you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. Please do not hesitate to contact us with your questions, contact details are below.

What is the purpose of the study?
People who experience seizures may experience a range of distressing emotions including worry, sadness, anger and shame. These can lead to people experiencing distress and may impact on their quality of life. People who have seizures may also experience other emotions which have not yet been researched. One of these emotions is self-disgust. By better understanding the relationship between seizures and certain emotions, such as self-disgust it may be possible to develop more effective treatments, such as psychological interventions. For this reason we would like to explore the emotion of self-disgust in people who experience seizures

Who can take part?
You are eligible to take part in this study if you:

- Have received a clinical diagnosis of epilepsy from a neurologist
- Experienced an epileptic seizure in the last 12 months
- Are over the age of 16
- Are English speaking or able to complete a questionnaire and interview in English
- You are able to provide informed consent to take part in the study.

Do I have to take part?
Your involvement in this study is entirely voluntary. We would like you to read this information sheet and think about what it would mean to you to take part. If you decide you would like to take part, you can complete the questionnaire included with this information, sign the consent form and return these to the researcher. You may contact the researcher should you have any questions and who can explain more about the study to you.

If you agree to take part in this study you are free to withdraw at any time without giving reason. This will not affect any care that you might otherwise be receiving.

What will happen if I decide to take part?
If you decide to take part in the study you will also need to sign a consent form saying that you agree to take part. You will then be asked to complete a questionnaire. This is a measure of feelings of self-disgust.

Approximately 12 of the participants who score high on this questionnaire, will then be invited to attend for a one-to-one interview with the researcher (Rebecca Mayor) to discuss their experiences of self-disgust in more detail. This can be in person or over the phone, whichever suits you best.

Participants who score low on the questionnaire will not be asked to take part in an interview. This is because this study is interested in hearing more from people who experience feelings of self-disgust. Data received from participants who score low on the questionnaire and are not invited to interview will not be used in the study and all information provided will be destroyed.

What will I have to do?
We ask that you read this information carefully. If you would like to hear more about the study or ask questions then you can contact the researcher to discuss this on 07508406193 or via email rmayor@lancaster.ac.uk

If you decide that you would like to take part in the study you can sign the consent form, complete the questionnaire and return these to the researcher in the envelope provided. Postage has already been paid. Alternatively, you can complete the questionnaire and consent form online. You need only complete the paper version OR online version. To access the online version of the questionnaire please use the following web address

https://eu.qualtrics.com/jfe/form/SV_bqp0Gp5Ava3lGEB

If you are selected to take part in an interview the researcher will contact you to discuss this and arrange a convenient time for this. The interview can be done in person or over the phone. The interview is expected to last around 1 hour. The researcher will ask you more about your experiences of having seizures, your emotions and responses to the questionnaire.

If you are not selected for interview you will be notified of this within 4 weeks of you consenting to take part in the study.

What are the possible disadvantages and risks of taking part?
There are minimal risks to taking part in this study. For some people, thinking or talking about emotions can be difficult. Should you feel distressed by any of the information you have read then talking to someone may help. You may wish to visit your GP to access support. Alternatively, a list of possible organisations who offer support is at the end of this information.

The interview will be conducted by a trainee clinical psychologist who is familiar with talking to people who might be upset or who have had similar experiences. Should you find the interview distressing you would have the opportunity to discuss this with the researcher and the option to stop the interview. The researcher will also be able to provide you with information about how to access further support.

What are the possible benefits to taking part?
We cannot promise that this study will help you but we hope that the information we get from this study will help to inform our understanding of emotions in people with seizures which may inform the development of support offered to people who may experience similar difficulties in the future.

What will happen to my data?
Your personal details and other information that you have provided will be stored electronically on the secure Lancaster University server. Paper documents (such as consent forms and questionnaires) will be scanned and then destroyed as soon as possible and saved in the same way. Electronic files will be password protected as an additional security measure. Interviews will be audio recorded, transferred to a computer and transcribed.
All electronic files will be transferred electronically using a secure method that is supported by the University for long term storage on the Lancaster University secure server for a maximum of 10 years.

What will happen to my data if I don't want to carry on with the study?
You may withdraw from the study without giving reason up until two weeks following an interview . If you decide to withdraw from the study before this time we will make all efforts to ensure that all data you have provided is destroyed and not used. This will not affect any care that you might otherwise be receiving. If you wish to withdraw from the study after longer than two weeks following interview we may not be able to remove the data you have provided from the study analysis.

How long do I have to decide whether I want to take part?
If you decide you would like to take part in the study please ensure you return the consent form and questionnaire enclosed with this information sheet as soon as possible**.**

What if there is a problem?
If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer your questions (Rebecca Mayor, tel:). Alternatively, you may wish to speak to my supervisor Dr Jane Simpson - Director of Education: J.simpson2@lancaster.ac.uk, Telephone: 01524 592858

If you remain unhappy and wish to complain formally, you may also contact: Professor Roger Pickup - Associate Dean for Research Email: r.pickup@lancaster.ac.uk Telephone: 01524 593746 Address: Division of Biomedical and Life Science Faculty of Health and Medicine, Lancaster University Lancaster, LA1 4YG, UK

Will my taking part in this study be kept confidential?
All information which is collected about you during the course of the research will be kept strictly confidential. We will allocate you a study number so all the information that you provide us with will be anonymous and stored separately to your contact details. Electronic copies of the consent forms and questionnaires will be stored securely and will be destroyed after 10 years.

Your name will be replaced with pseudonyms to make these anonymous during the transcription process and only anonymised quotes would be used in publications.

Will you tell anyone else I have taken part?
We will not routinely share your involvement with anyone else. However, if you share any information with the research team which leads us to worry about your, or someone else's, safety, then we may be required to share this information in order to maximise safety.

Data collected during the study may occasionally be shared with the research team or members of the NHS Trust. However, only your study number will be shared. No identifiable information such as your name will be shared.

What will happen to the results of the study?
The results of the study will be summarised and written up to be used as part of academic work towards a postgraduate degree for the researcher (Rebecca Mayor). All information will be anonymous and no identifiable data will be used. The results of this study will also be published in a peer-reviewed journal (again, no identifiable information will be published).
A shorter summary report will also be sent to the organisations which advertised the study. You may request a copy of this shorter report if you wish from the researcher.

Who is sponsoring the research?
This study is being sponsored by Lancaster University under the Research Governance Framework.

Who has reviewed the study?
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 xxx Research Ethics Committee.

Further information and contact details
You can contact Rebecca Mayor (email: r.mayor@lancaster.ac.uk or tel: 07508406193) if you have any questions about the research or want to discuss your involvement. You may talk to others about the study if you wish.

Possible sources of support

Mind Website: http://www.mind.org.uk/ Telephone: 0300 123 3393

Samaritans Website: http://www.samaritans.org/ Telephone: 08457 90 90 90

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

Thank you for taking time to read this sheet and considering whether to take part in this study.

Appendix 4-E. Invite

Experiences of the emotion of self-disgust in people with seizures

Previous research has shown that how people feel about themselves can have important effects on their quality of life and even the outcome of health problems. Feelings such as anger, shame, guilt, worry may all be relevant. One emotion which has attracted attention recently is self-disgust.

On behalf of the Lancaster University Clinical Psychology Doctorate programme, I am looking for participants to take part in a study looking into the experiences of certain emotions in people with seizures. In particular, this study will consider the emotion of self-disgust.

Participation involves completing a short questionnaire and then the possibility of an in-depth interview with the researcher. Before deciding to take part you will have the opportunity to read some more detailed information about why the study is being done, who can take part and what it would involve for you.

If you would be interested in hearing more about the study you are welcome to contact the researcher (Rebecca Mayor) by phone on xxx or email r.mayor@lancaster.ac.uk The researcher will explain the study to you and will answer your questions.

Please follow this link for more information and to take part in the study

[insert link here]

Experiences of difficult emotions in people with seizures

Previous research has shown that how people feel about themselves can have important effects on their quality of life and even the outcome of health problems. Feelings such as anger, shame, guilt, worry may all be relevant. One emotion which has attracted attention recently is self-disgust. On behalf of the Lancaster University Clinical Psychology Doctorate programme, I am looking for participants to take part in a study looking into the experiences of self-disgust in people with epilepsy.

Participation involves completing a short questionnaire and then the possibility of an in-depth interview with the researcher. An information sheet is enclosed which provides you with more information about why the study is being done, whether you are eligible to take part and what it would involve for you. Please consider this information before deciding whether or not you would like to take part in this study.

If you would be interested in hearing more about the study you can complete the 'Consent to Contact' form to receive a phone from me to hear more about the study. You can also welcome to contact me by phone on xxx or email r.mayor@lancaster.ac.uk if you have any further questions.

If you would like to take part in the study you can complete the consent form and questionnaire and return these to me in the stamped addressed envelope (postage is already paid). Alternatively, you can complete these online by following the below link. [insert link here] You need only complete the paper OR online version of the consent form and questionnaire.

Thank you for your time in considering this study.

Kind Regards

Rebecca Mayor

Trainee Clinical Psychologist

Appendix 4-F. Consent

CONSENT FORM

Study Title: Experiences of difficult emotions in people with seizures

Researcher: Rebecca Mayor

If you wish to take part in the research study please initial and sign this form.

Please initial each box

1. I confirm that I have read and understand the Participant Information Sheet Version (*v4, 05/04/2017*) and I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw from the study at any time without giving any reason. I understand that this will not affect any care that I might be receiving. ☐
3. I understand that the researcher has a professional responsibility to share information I provide if they believe I am at risk of harming myself or someone else in order to maximise safety. ☐
4. I agree to take part in an interview which will be audio recorded and transcribed for further analysis. ☐
5. I agree that anonymised parts of the interview recording and transcript can be used for publications and for educational purposes. ☐
6. I understand that relevant sections of data collected during the study may be looked at by members of the research team from Lancaster University, regulatory authorities or representatives from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
7. I agree to take part in the research. ☐

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Name of person taking consent	Date	Signature

CONSENT FORM: ONLINE

Study Title: Experiences of difficult emotions in people with seizures

Researcher: Rebecca Mayor

Before you consent to participating in this study we ask that you read the participant information provided. Please read the following statements and tick the box below if you are happy to take part in the study.

1. I confirm that I have read and understand the Participant Information Sheet Version 4, 05/04/2017 and I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw from the study at any time without giving any reason. I understand that this will not affect any care that I might be receiving.

3. I understand that the researcher has a professional responsibility to share information I provide if they believe I am at risk of harming myself or someone else in order to maximise safety.

4. I agree to take part in an interview which will be audio recorded and transcribed for further analysis.

5. I agree that anonymised parts of the interview recording and transcript can be used for publications and for educational purposes.

6. I agree to take part in the research.

Appendix 4-G. Questionnaires

Demographic Questionnaire

Name:

Age (in years):

Sex: Male Female Prefer not to say

Contact telephone number:

Contact email address:

Diagnosis: (Please indicate if you received a diagnosis of epilepsy)

How long ago did you receive this diagnosis?

The Self-Disgust Scale (SDS)

This questionnaire is concerned with how you feel about yourself. When responding to the statements below, please circle the appropriate number according to the following definitions: 1 = Strongly disagree; 2 = Very much disagree; 3 = Slightly disagree; 4 = Neither agree nor disagree; 5 = Slightly agree; 6 = Very much agree; 7 = Strongly agree.

	Strongly disagree						*Strongly agree*
1. I find myself repulsive.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
2. I am proud of who I am.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
3. The way I behave makes me despise myself	**1**	**2**	**3**	**4**	**5**	**6**	**7**
4. I hate being me	**1**	**2**	**3**	**4**	**5**	**6**	**7**
5. I enjoy the company of others.	**1**	**2**	**3**	**4**	**5**	**6**	**7**
6. I like the way I look	**1**	**2**	**3**	**4**	**5**	**6**	**7**
7. Overall, people dislike me	**1**	**2**	**3**	**4**	**5**	**6**	**7**
8. I enjoy being outdoors	**1**	**2**	**3**	**4**	**5**	**6**	**7**
9. I feel good about the way I behave	**1**	**2**	**3**	**4**	**5**	**6**	**7**
10. I do not want to be seen	**1**	**2**	**3**	**4**	**5**	**6**	**7**
11. I am a sociable person	**1**	**2**	**3**	**4**	**5**	**6**	**7**
12. I often do things I find revolting	**1**	**2**	**3**	**4**	**5**	**6**	**7**
13. Sometimes I feel happy	**1**	**2**	**3**	**4**	**5**	**6**	**7**
14. I am an optimistic person	**1**	**2**	**3**	**4**	**5**	**6**	**7**
15. It bothers me to look at myself	**1**	**2**	**3**	**4**	**5**	**6**	**7**
16. Sometimes I feel sad	**1**	**2**	**3**	**4**	**5**	**6**	**7**
17. I detest aspects of my personality	**1**	**2**	**3**	**4**	**5**	**6**	**7**
18. My behavior repels people	**1**	**2**	**3**	**4**	**5**	**6**	**7**

Appendix 4-H. Debrief

Participant Debrief Sheet

Research Study Title: Experiences of difficult emotions in people with seizures

Thank you for completing the questionnaire and helping in this research study. We realise that some people can find some questions distressing. If you have been upset by the questionnaire and would like further support, the following organisations may be able to help you:

Possible sources of support

Samaritans Website: http://www.samaritans.org/ Telephone: 08457 90 90 90 (24 hour, Freephone)

Mind Website: http://www.mind.org.uk/ Telephone: 0300 123 3393

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