

## **Abstract**

***Aim:*** To explore 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, with the final theme illustrating 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 appeared to become internalised following others' disgust reactions. Avoidance as a strategy to manage self-disgust could be protective but might have inadvertently maintained feelings of self-disgust.

***Keywords:*** Epilepsy; Emotions; Disgust; Self-disgust; Qualitative

## **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]. Indeed, 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 the ‘diagnosable’ conditions of anxiety and depression. Individuals with epilepsy are subject to high levels of stigma, which has established associations with a number of uncomfortable emotions [4]. For example, recent research has indicated that people with epilepsy are more likely to experience negative self-directed emotions such as shame, guilt, [5] and embarrassment [6] which are associated with higher levels and more severe symptoms of anxiety and depression, as well as poorer quality of life [7]. As a result of such emotional experiences, individuals may experience increased social avoidance and poorer relationships [8].

### **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, as a universal human emotion [11], is now seen to be 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] and which can be triggered by a wide range of ‘core’ elicitors

(faeces, bodily contaminants etc.) and more sociocultural factors [12]. Moreover, more recently, there has also been increased interest in the transdiagnostic construct of self-disgust. However, unlike disgust, self-disgust is conceptualised as a dysfunctional, rather than adaptive, generalisation of the disgust response, directed towards the self [13,14].

While self-disgust has been confused with other self-conscious emotions such as shame, guilt [15] and self-criticism [16], over the last decade it has been increasingly seen as a psychometrically valid separate construct, with clinical utility [see 17 for a comprehensive review]. Self-disgust is conceptually delineated from these other negative self-referent emotions mainly through its relation to disgust and revulsion [12, 18, 19]. For example, the visceral and pervasive nature of self-disgust (often experienced as physical feelings of nausea), as well as distinct disgust-based appraisals [15], are specific to self-disgust. Moreover, 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 specific psychological and behavioural reactions (such as attempts to cleanse or remove the disgusting self) not evident in other emotions [15, 17, 20, 21, 22]. 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].

In order to help understand under what circumstances self-disgust might develop, it has been theorised as a distinct emotion schema [12, 15]. Emotion schemas can be defined as experience-derived associations including perceptions, emotions, appraisals and cognitions [23]. It has been argued that, as with other such schemas, self-disgust is likely to develop in childhood, perhaps in response to disgust based abuse, but can also develop in adulthood, usually as a 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 depression, body image difficulties and trauma [17]. Further, the concept of self-disgust and its role in adaptation to physical health conditions has also been evidenced [25]. The physical and disgust eliciting side-effects of cancer treatments, such as nausea or bladder or bowel problems, have been associated with increased psychological distress and have been shown to mediate adjustment to cancer treatment [26, 27, 28].

### **1.3 Epilepsy, Disgust and Self-disgust**

Exploring self-disgust in relation to epilepsy may be particularly relevant. Epilepsy is a disorder associated with very visible potentially disgust-inducing behavioural consequences such as convulsions or incontinence that could result in the activation of a previously developed 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 could also develop in response to others' reactions to epilepsy [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 was considered by early Christian writers to be caused by an "unclean dumb and deaf spirit" (p. 12) [32], illustrating the long-standing nature of the negative beliefs held about the condition. Individuals with epilepsy may therefore have to manage a number of 'disgusted' reactions from others arising from being perceived as contaminating and socially stigmatised [33]. Indeed, in a study with a similarly stigmatised group, parents of children with disfigured faces reported avoiding taking their children out in public due to the anticipated disgust reactions of others [34]. Moreover, 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 [35, 36]. 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 [37].

#### **1.4 Current Research Question**

While there is a theoretical case for the experience of self-disgust in people with epilepsy, this is currently empirically unexplored. Consequently, the current study addresses this gap by exploring first-hand perspectives of people with epilepsy. Given the aim of the study, a qualitative methodology was used with the specific research question: how is self-disgust experienced and understood in individuals with epilepsy?

## **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]. 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 relevant 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 an appropriate methodology for the current study.

### **2.2 Procedure**

The necessary ethical approval for research carried out within the UK 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 charity staff and via 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 only a proportion would be invited to 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. 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 to identify a sample 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.

Interviews were conducted according to a semi-structured schedule (see Appendix 1). This was based on a previous study which qualitatively explored the experiences of self-disgust in women with depression [15], but which was adapted for the current research study. This allowed for discussion of the participants' history of 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 in that they could freely move the content to areas relevant to their experiences.

## **2.3 Participants**

Forty-three participants, all recruited from online sources, completed the SDS and consented to take part in the research. The median score on the SDS was 50 (inter-quartile range = 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]. Additionally, while we are aware that data saturation is a concept often used to justify sample size in qualitative research, it was not used in this study. Instead, because of a number of factors including approach to analysis and the highly selective nature of the sample, we adopted the alternative concept of information power. We initially considered 10 to be a suitable number based on these factors and, while reviewing this throughout the data collection period, felt that this was justified.

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 had 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.

- 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]. The approach involved six phases: 1. Familiarisation with the data. 2. Generation of initial codes. 3. Search for themes. 4. Review of themes. 5. Definition and naming of themes. 6. Production of 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 preconceptions [43]. In line with guidance, interviews were transcribed verbatim by the researcher, which aided familiarisation. 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 were not prematurely abandoned [44]. The analysis started from a relatively broad perspective (although still focussed on content related to the research question) and was distilled into three potential initial themes through the data analysis process.

These 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 Ensuring quality**



Many quality appraisal tools and criteria can often not be suitably applied to qualitative research. However, to demonstrate trustworthy findings, qualitative research and, specifically thematic analysis, should be conducted and reported in a rigorous manner that is consistent with its own paradigmatic underpinnings [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 and discussion of the results within the supervisory team. Notes were made to track reflections and lines of enquiry following both the interviews and the analysis process [47]. 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. An audit trail of the analytic process is available on request, allowing readers to judge the reliability of interpretations by detailing the development of the themes from raw interview data.

### **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 interpretations.

#### **3.1 Being an outsider: “The feeling of being a bit of a freak”**

In this first theme, participants described the difficulties caused by the physical symptoms of seizures and the further challenge of seeing others’ negative reactions. Participants described the disgust responses from witnesses as inevitable and the other

subsequent negative reactions led participants to feeling stigmatised, internalising the disgust they observed from others and anticipating further negative appraisals and rejection.

All participants described the physical symptoms of their seizures as unnatural, dangerous, and posing a 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 'core' disgust-inducing symptoms associated with seizures (e.g., bodily secretions). Furthermore, symptoms of seizures also appeared to result in a different type of disgust responses ('socio-moral' disgust), 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 strong, specific disgust response.

Due to their disgust-inducing nature, 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 fear also drove a desire by participants to prevent others’ perceptions of them being enduringly associated with their epilepsy: “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). Furthermore it led to Anne feeling ‘dirtied’ and 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 from 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 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). 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 theme, participants described the enduring nature of self-disgust due to the uncertainty of epilepsy. Self-disgust could be activated through both memories or reminders about epilepsy without the physical reality of a seizure and the potential to cause distress to others as a result of further seizures. 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 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. 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-elicite 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 a number of 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 children’s 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 its pointlessness, 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 was 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 how they changed or adapted 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 as adaptive responses 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 to 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 to attempt 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 others’ resulting negative reactions. One participant specifically described this as 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 an attempt to limit further seizures and 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 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 [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 in others as a result of the physical presentation of seizures and associated side-effects including secretion of bodily 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, participants' activation of their own 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 ensuring 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 the visceral experiences of sickness and nausea specific 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 emotion schema. Emotion schemas represent interactions between perceptions, emotions, appraisals and cognitions [23] and are hypothesised to be remain at some levels of consciousness [48]. Thus, participants described a self-disgust emotion schema which was enduring and palpable in the background, but which could also be triggered by congruent experiences and therefore experienced more strongly.

While it has been proposed that the self-disgust schema is likely developed in childhood [13], it has more recently been argued that dysfunctional self-disgust schemas can be created in adulthood, particularly in those with later onset of a chronic, debilitating physical condition [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 the epilepsy 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, some 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 managing a long-term health condition [49]. 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 [50]. 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 and to prevent their epilepsy distressing others. It has been proposed that disgust may have a causal link to stigma in health conditions such as cancer [28]. Theoretically, social avoidance in cancer has been proposed to have beneficial effects both in the short and longer term [51], for example in the maintenance of relationships. However, differences between health conditions in terms of elicitors of disgust are of important note as is their perceived curability and chronicity. 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 [52]. Moreover, the mediating impact of self-disgust on loneliness and depression has been described [53]. 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 [54].

#### **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 verify this information. For this reason, it is possible that the sample reported on here included those with non-epileptic seizures and, given they were likely to have different psychological experiences from those with epilepsy [55], 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 large - scale quantitative studies which also rely on self-reported diagnosis, may indeed face this challenge [56].

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 [57]. 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. Methodologically, a further limitation was the fact that the coding of interview transcripts was only conducted by the first author, although attempts to ensure quality involved the wider research team being involved in discussions around analysis and ensuring that codings and interpretations were justifiable.

### **4.3 Clinical Implications**

It is important to emphasise that this study is not concluding that self-disgust is present in all people with epilepsy and that these results are somehow generalisable to the population as a whole. It, instead, provides a detailed account of the experience of self-disgust from those who have originally identified themselves, from the recruitment process, as expressing this emotion and who scored high enough on a relevant scale to be approached to talk in-depth about their experience. However, 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 and should at least be explored. 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 [58]. 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.

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 has been recognised as an important factor in adjustment to physical health conditions [59]. 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.

Therapeutic interventions for associated emotions such as guilt and shame have been described, for example mindfulness and present moment acceptance [27], compassion-focused therapy [45] and exposure therapy directed towards disgust at one's own body [60]. Indeed it has been proposed that emotional components are of key consideration in psychological interventions aimed at reducing negative self-directed emotions [61]. More recently, experimental work has also suggested that self-affirmation may be helpful in reducing in-the-moment self-disgust [62]. 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 [63],



societal approaches aimed at improving understanding and 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.

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Table 1: Participant clinical and demographic characteristics

Pseudonym	Age (years)	Gender	Years since diagnosis	Self-disgust scale score (SDS)
Helen	30	female	3	49
Sue	43	female	23	56
Gemma	26	female	1	59
Sam	28	male	20	71
Katie	24	female	13	57
Laura	31	female	.5	57
Harriet	22	female	3	60
Neil	62	male	47	62
Anne	60	female	12	60
Clare	29	female	8	64



## Appendix 1

### Semi-structured interview schedule

The interview was mostly guided by the participant but the guide below was used to structure the conversation. Follow-up questions and prompts were provided when necessary.

1. Introduction to the purpose of the interview, i.e. to talk about participants' experience of difficult emotions, in particular self-disgust.
2. Questions were asked about participants' perspectives of epilepsy to help understand their point of view better. These included: i) Brief background about their epilepsy and current situation; ii) How long ago did seizures start/ receive the diagnosis? iii) What happens / how often do they happen?; iv) What impact does having epilepsy have on life currently?; v) Are there activities/situations that are difficult as a result of having seizures?
3. Completion of the self-disgust scale: How did the participant find completing the questionnaire on feelings of self-disgust? What were the participants' thoughts or feelings as a result of this?
4. Experiences of difficult emotions and self-disgust: Can participants describe their experiences of self-disgust? Please give as much detail as possible. Are there any thoughts or feelings related to these experiences? Can participants describe times when they have felt disgusted with themselves? Can they think of any specific examples that could be shared? What did participants think made them feel self-disgust then? What prompted these feelings? How do feelings of self-disgust affect them? Was there anything they did more of/ less of/ differently?

5. Coping with self-disgust: How did participants manage feelings of self-disgust? Was there anything which helped cope with/avoid these feelings? Were participants able to reduce these feelings?
6. Other feelings/cognitions: How did participants feel about their experiences of self-disgust? Were there any other emotions associated with this? What thoughts did they have you themselves generally?
7. Was there anything that makes them feel more positive? Can participants describe times or situations when they felt less self-disgusted. Were there times when participants were more confident? What positive thoughts/emotions did participants have in these circumstances?
8. Development of self-disgust and relationship with seizures: When did feelings of self-disgust first emerge? Was this before having seizures? Have feelings of self-disgust varied more or less over the illness period? Was there any perceived relationship with the course of condition? What effects do the feelings have on condition? What aspects of behaviour are more affected?
9. Debrief and references to sources of support.