An Interpretative Phenomenological Analysis of the Experience of Self-Disgust in People with Functional/Dissociative Seizures

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Abstract

Background

Previous research in individuals with epilepsy suggests that some of the physical, disgust-eliciting manifestations of seizures may trigger self-disgust. Self-disgust has previously been linked to experiences of emotional neglect and trauma, especially in childhood. Both these are more common in people with functional dissociative seizures than in those with epilepsy. Hence, this study aimed to understand the experience of self-disgust in people with functional/dissociative seizures (FDS).

Methods

This qualitative study used interpretative phenomenological analysis (IPA). Following initial screening using the Self-Disgust Rating Scale, purposive sampling was used to recruit eight eligible participants with high levels of self-disgust to participate in individual semi-structured interviews.

Results

In the larger sample (n = 108), 85.2% of participants reported high levels of self-disgust. The exploration of the phenomenology of self-disgust in a group of high scoring individuals produced four themes: ‘understanding the origin of self-disgust as based in rejection’, ‘experiencing self-disgust as intense and inescapable’, ‘understanding the relationship between self-disgust and FDS’ and ‘suppression and seclusion - attempting to cope with self-disgust’.

Conclusions

Self-disgust may be highly relevant to a subpopulation of pwFDS and may arise from the internalisation of traumatic, seizure-related experiences. While attempts to reduce self-disgust may provide short-term relief, these could reinforce and maintain the underlying cognitive-affective state. Although often under-recognised, it is important to assess for the presence of self-disgust in clinical settings and to offer additional support around engagement and therapeutic alliance development. A number of therapeutic and systemic approaches to address high levels of self-disgust are discussed.

Keywords: functional/dissociative seizures; self-disgust; qualitative; interpretative phenomenological analysis

1.1 Introduction

Functional/dissociative seizures (previously known as psychogenic nonepileptic seizures or nonepileptic attacks) are episodes of reduced consciousness that involve involuntary movements or changes in sensation and perceptions [1]. Functional/dissociative seizures (FDS) resemble epileptic seizures but are not associated with ictal epileptiform discharges in the brain [2]. FDS are one manifestation of functional neurological disorder (FND) [3].

FDS are thought to be caused by an interplay of psychological, social and biological factors, often associated with psychological stressors [4]. The prevalence of FDS has been calculated as 23.8/100,000 [5], although this estimate is tentative due to a lack of reliable studies [6,7]. Support from multi-disciplinary professionals is recommended [e.g. 8], however, the most frequently recommended treatment is psychological therapy [9].

FDS are commonly associated with psychological distress. Patients with FDS have higher rates of mental health disorders than the general population, including anxiety and depression [10], and higher rates of suicide [11]. Post-traumatic stress disorder occurs in 38-64% of people with FDS (pwFDS), with high rates of childhood trauma and adverse life events [12] Additionally, over 90% of pwFDS report the detrimental effects of stigma. This includes external stigmatisation manifesting in reduced healthcare access and adverse healthcare experiences [13], as well as the consequences of internalised stigma in the form of negative self-conscious emotions [14,15,16]

Self-conscious emotions, including guilt, embarrassment and shame, can be distinguished from basic emotions (such as fear or anger) by their self-referential nature - they involve the self as both subject and object of evaluation [17]. They do not only impact an individual's self-image and personal identity goals but also how they are viewed by others

[17,18,19]. Such emotions are often experienced negatively, particularly when related to trauma [20] and health concerns [21,22]. Existing studies show that pwFDS commonly experience negative self-conscious emotions such as shame [e.g. 23], embarrassment [24] and low self-compassion [25]. Additionally, in a recent qualitative study, self-disgust was found to be a highly relevant emotion in a substantial proportion of individuals with epilepsy, i.e. another condition characterised by unpredictable seizures and (mostly) invisible disability [26].

Self-disgust is a maladaptive generalisation (or internalisation) of the basic emotion of disgust, but directed towards oneself [27]. Disgust is a universal, basic emotion developed to promote self-preservation by avoiding potential contaminants [28]. Disgust can be triggered by a range of elicitors such as bodily contaminants and secretions, undesirable physical attributes, certain animals and their secretions, unsanitary environments, sociomoral violations and immoral character traits [29]. As with other basic human emotions, disgust can become dysfunctional resulting in the development and propagation of a number of mental health difficulties [28]. Moreover, disgust reactions can also be self-elicited [30].

Self-disgust can be delineated from other self-conscious emotions such as shame and guilt due to its relationship with revulsion and disgust [31]. For example, the visceral nature and distinct disgust appraisals (e.g. “I make people feel sick”) are specific to self-disgust [31]. One can experience feelings of shame or guilt without disgust, and vice versa [27]. Another distinguishing aspect of self-disgust is the psychological and behavioural responses it elicits. While both shame and disgust can lead to social avoidance, self-disgust can also result in self-cleansing or dissociating from the “disgusting self” [p.124, 32].

Self-disgust is likely to be relevant in FDS for a number of reasons. Firstly, in the previous study involving individuals with epilepsy [26], participants' self-disgust was, in part, attributable to the disgust reactions of others to the physical manifestations of seizures. Specifically, the elicitation in others of disgust was often in response to a key typical trigger of the disgust response: the presence of pathogens (e.g., bodily fluids) which emerged during seizures [29]. A similar process might be expected in pwFDS who also experience seizures.

Secondly the diagnostic uncertainty associated with FDS opens up the space for more harmful and blaming social attributions such as 'they should control themselves' or 'there is nothing medically wrong with them' [13]. These are clearly misattributions but they can arise more strongly when a medical condition is not socially validated [33]. This therefore raises 'moral disgust' as an additional trigger to causing self-disgust in pwFDS [29]. Moral disgust occurs as a response to behaviours that are perceived as violating social or ethical norms, such as cheating, deception, exploitation, or unfairness. [34]

Moreover, given FDS's previously established links with trauma and emotional neglect (especially in childhood), as well as a range of mental and physical health conditions, we wanted to examine the possible role and phenomenology of self-disgust in patients with FDS. Given that rates of trauma and emotional neglect (especially in childhood) as well as rates of comorbid mental and physical health disorders are much higher in pwFDS than in those with epilepsy [35, 36], we did not only expect to find that self-disgust would arise in people FDS as a result of having seizures but that it may also be an important factor contributing to the development of FDS. No previous research has explored the experience of self-disgust in pwFDS. Better understanding of self-disgust in FDS could also have clinical benefits, improving clinician awareness of how this emotion is experienced to inform assessment, formulation and interventions for pwFDS. Consequently, the aim of this study was to gain an in-depth, rich understanding of subjective experiences of self-disgust in pwFDS to address the research question: how is self-disgust experienced and understood by individuals with FDS?

2. Methodology

All aspects of this project were performed in compliance with institutional guidelines; ethical approval (no: 050804) was granted by the University of Sheffield for this study in 2022.

2.1 Research Design

A number of qualitative research methods were considered in developing the most appropriate methodology to answer the research question. Interpretative phenomenological analysis (IPA), a widely-used and valued method within clinical and health psychology research [37], was selected for a number of reasons. Firstly, its focus on idiography allows for close engagement with the unique features of each participant's account before developing themes across the dataset. Secondly, its emphasis on hermeneutics enables a nuanced and

detailed understanding of how humans experience and understand a particular phenomenon [38]. Finally, its grounding in phenomenology emphasises the need to provide rich, detailed accounts of an experience.

2.2 Participants

Initially, 108 participants - adults who experienced FDS - completed the Self-Disgust Rating Scale [SDS; 39]. Purposive sampling was used to recruit eight of the highest scoring participants for semi-structured interviews. This sampling strategy aimed to capture a reasonably homogenous sample of participants who could represent a perspective on self-disgust in FDS [40]. Homogeneity on parameters relevant to the research question allowed a rich and meaningful exploration of the subjective experience of self-disgust in FDS [40]. IPA benefits from a concentrated focus on a small number of participants, balancing the ability of the researcher to absorb and process the experience of each individual in-depth, and identifying recurrent observations across the group [40]. Therefore, eight participants were considered sufficient to produce rich data to address the research question [40]. The inclusion and exclusion criteria applied to those invited to participate in interviews are summarised in Table 1.

Table 1 around here please

Demographic information of interview participants was collected (Table 2). Most participants were female (n = 7), aged 28-59 (M = 43.5). Years experiencing seizures ranged widely (range = 3-34), with participants experiencing seizures for an average of 15 years.

Table 1

Study inclusion/exclusion criteria

Inclusion Criteria	Justification/Notes
Aged 18 years or over	This research focuses on adults and to manage ethical considerations around consent and safeguarding [41]
UK resident	To keep the sample fairly homogenous [40]
Have a formal diagnosis of FND, and experience functional/dissociative seizures with loss of consciousness	FND is a broad and heterogeneous category [42]. Focussing on one subset of the condition can keep the sample fairly homogenous [40]
Score >31 on the Self-Disgust Scale [43]	The rationale for this cut off is explained in the measures section below. This was to identify people for whom self-disgust was most relevant
Is willing and able to be interviewed in English	Although it was recognised that the study would potentially lose valuable insights from non-English speakers, due to the hermeneutic nature of IPA, it would be difficult to interpret an individual's unique experiences of self-disgust from their own language use through interpreted

	interviews [42]. Therefore, interviews were conducted in English to allow for in-depth insights from the individual's perspective [40].
Exclusion Criteria	**Justification/Notes**
If the participant does not have the capacity to consent	For ethical reasons [41]
Unable to access the internet or phone	Participants will be required to access the internet or phone to participate in the research interview

Table 2

Participant Demographics

Participant	Age	Gender	Ethnicity	Education Level	Employment Status	Year diagnosed with FDS	Years experiencing seizures	Self-disclosed difficulties	SDS score
Grace	41	Not specified	White British	Further Education	Unemployed	2023	34	Dissociative Identity Disorder C-PTSD* Myalgic Encephalomyelitis	80
Sarah	28	Female	White British	Further Education	Unemployed		13	PTSD Elher-Danlos Syndrome Borderline Personality Disorder Depression	78
Jane	42	Female	White British	Further Education	Medically retired	2019	>30	Fibromyalgia Learning Difficulties	71
Rachel	50	Female	White Other	Post-graduate Education	Unemployed	2022	6	Depression	79
Steve	59	Male	White British	GCSE	Unemployed	2018	8	Anxiety Depression	79
Lauren	38	Female	White British	Undergraduate Education	Unemployed	2022	3	Fibromyalgia Anxiety Depression	71

Helen	50	Female	White British	GCSE	Unemployed	2023	20	Eating Disorders Tourette's Syndrome Obsessive Compulsive Disorder	72
Kelly	40	Female	White British	Further Education	Unemployed	2018	6	Borderline Personality Disorder Complex Posttraumatic Stress Disorder Depression Anxiety Underactive Thyroid Myalgic Encephalomyelitis	73

2.3 Participant and Public Involvement (PPI)

Feedback was sought during development of the study on proposals and study materials from experts by experience and professionals in the field. A member of the UK charity FND Dimensions provided feedback on the interview schedule and information sheet.

2.4 Materials

2.4.1 Measure

To measure self-disgust and identify participants eligible for interview, the *Self-Disgust Scale* [39] was used. This is an 18-item self-report measure with four items each relating to one of three self-disgust constructs: appearance, general self-concept and behaviour (and six neutral filler statements). It has a 7-point Likert scale (1= *strongly agree,* 7 = *strongly disagree).* Possible scores range from 12 to 84, with higher scores indicate greater self-disgust. The SDS has good internal consistency (α = .91; [39]; α = .88; [43]). As in previous studies exploring self-disgust in clinical populations [26, 31], participants who scored greater than 31 (more than one standard deviation above the mean in non-clinical samples [39], were considered for interview.

2.4.2. Semi-structured interview

Verbal semi-structured interviews are commonly used in IPA, based on the approach's aims of understanding the individual's story [40]. The interview schedule used in this study (see Supplementary Appendix 1) was informed by the study's aims and relevant literature [40], and developed in consultation with stakeholders.

2.5 Procedure

FND Action, a specialist UK FND charity, agreed to support recruitment for this study. A study advert was shared on their X (formerly Twitter) feed and website. The advert specified the topic of this study was 'difficult emotions' to reduce the risk of negative reactions to the study topic before participants reached the information sheet, where the more specific focus of the study was disclosed. Participants accessed a Qualtrics survey to read the participant information sheet, complete a consent form, and complete the SDS. The online survey specified a cohort would be invited to take part in a further in-depth qualitative interview and consent to be contacted for this was gained. Participants were given a debrief sheet at this point. Online recruitment took place in September-October 2023.

The 20 participants with the highest SDS scores were contacted, by email, to be invited to interview. Eleven people responded to invitation, but three cancelled or did not attend, resulting in eight interviews being conducted. Interviews took place between November-December 2023. Before interview, all participants provided informed consent. Confidentiality and withdrawal rights were explained, and participant demographic information was gathered at the beginning of the interview. Semi-structured interviews were then conducted by the first author over approved video technology. The median interview duration was 84.5 minutes (M = 86.37). The interviews were transcribed verbatim.

2.6 Data Analysis

Interview transcripts were analysed by the first author using an inductive and iterative approach, following IPA guidelines described by Smith et al. [40] and Murray and Wilde [44]. Firstly, each participant's transcript was read and audio-recordings listened to on repeat to facilitate immersion in the data. Exploratory noting and coding was then completed. Exploratory notes were organised and summarised in experiential statements that captured an understanding of the participant's original words, thoughts and interpretations. These

experiential statements were then organised and grouped into personal experiential themes (PETs), with interpretative narrative summaries produced for each PET [44]. This process was repeated for each participant and treated as an independent inquiry (see Participant Representation Matrix in Supplementary Appendix 1). Group experiential themes were then created which highlighted the similarities and differences between experiences across participants. During the analysis, the first author identified, set aside, or held in awareness her own assumptions, beliefs, and prior experiences (i.e. these were 'bracketed') so they did not dominate the participant's meaning-making [40].

2.7 Research Quality

To ensure research quality, the following principles for evaluating IPA study quality were followed [45]: constructing a compelling, unfolding narrative; developing a vigorous experiential and/or existential account; close analytic reading of the participants' words; and attending to convergence and divergence. These quality aims were achieved, for example, by: grounding researcher interpretations in the available data, with verbatim examples provided to demonstrate theme development and a coherent narrative; extensive use of illustrative quotes accompanied by analytic commentary; close analytic reading of transcripts to explore their significance and fuller meaning, within a context of reflective practice; creation of comprehensive audit trails (see supplementary materials); and commitment to exploring both participant similarities and differences to demonstrate patterns of connection while highlighting participants' unique experiences [47].

2.8 Reflexivity

In all qualitative studies, it is important to be transparent about positionality - i.e. researchers' social, cultural and political identities - and their relationship to the research context as this shapes how they interpret data, interact with participants and influence knowledge

production. [46]. The first author, who collected and analysed the data, was a female, trainee clinical psychologist, with no personal experience of a long-term health condition or functional symptoms and who had never worked closely with a pwFDS. She kept a reflective diary throughout the research process to maintain awareness of how her perspectives influenced the study. The other authors were a clinical psychologist (JS) with an academic interest in self-disgust but little experience of FDS and a consultant neurologist (MR) with extensive experience in FDS. All authors expected self-disgust to feature in participant accounts, given previous research in this area and (for MR) clinical experience of participant accounts. However, the nature and extent of it was unclear for all. While the analysis was conducted by the first author, all aspects related to theme development were interrogated by the other authors, with any interpretations lacking a clear empirical base challenged and, if not able to clarified, removed.

3. Results

The majority (85.18%) of participants scored above 31 and were therefore eligible to participate in the interview. The mean SDS score across the larger sample was 52 (*SD* = 16.24), suggesting high levels of self-disgust. The mean SDS score among participants interviewed was 75.37 (*SD* = 3.96).

The IPA analysis produced four GETs with subthemes (Table 3).

Table 3

Group Experiential Themes and subthemes

GET	Sub-theme
Understanding the origin of self-disgust as based in rejection	- A history of abuse laying the foundation for self-disgust

	- Others' repulsion introducing shame and disgust for FDS
Experiencing self-disgust as intense and inescapable	- A chronic and unchangeable belief - An intense emotional experience
Understanding the relationship between self-disgust and FDS	- Seizures and self-disgust: A vicious cycle - Deviation from the medical norm: Disgust for FDS - A drain and a burden: Self-disgust related to disability
Suppression and seclusion- attempting to cope with self-disgust	- Avoiding exposure through social withdrawal - Emotionally suppressing the unbearable self-disgust - Physically hiding oneself to deny the reality of self-disgust

3.1 Understanding the origin of self-disgust as based in rejection

This theme relates to participants' negative experiences with others and their understanding of how this contributed to the development of their negative self-concept and, subsequently, self-disgust. Two distinct experiences of rejection emerged: through a history of abuse and external repulsion by the public for their FDS.

3.1.1 Historical abuse laying the foundation for self-disgust

Most participants had experienced abuse from others which created a sense of inferiority and worthlessness, fuelling an "*inner-critic*" (Kelly) that led to shame regarding who they were.

> "*So, that all comes from emotional abuse from my mother, like nothing was ever good enough, always questioned everything I ever did, just made me feel pathetic,*

you know? And if I did get something right it was…"You stupid bitch" I get called, and I think it's just an accumulation of all that sort of stuff" (Kelly)

For some, shame and disgust-based bullying during adolescence permanently damaged their self-esteem and body image. The relentlessness of the criticism led to messages becoming internalised. Bullying made Jane feel ashamed of health conditions and confirmed her body was disgusting, to the extent she was unworthy of living.

"Oh I've been called… smelly, trampy, pisshead, I was told that I was a waste of space, I was told that erm I would have been better off dead." (Jane)

Four participants had experienced sexual assault, from which intense distress and disgust left them with a perpetual sense of being contaminated by something repulsive: *"I never feel clean, ever feel clean"* (Helen). Unable to cleanse the self from these feelings, they became internalised, eventually culminating in self-disgust.

3.1.2 Others' repulsion introducing shame and disgust for FDS

All participants received negative reactions for having seizures due to a "*massive lack of knowledge*" (Sarah) about FDS, leading to troubling public experiences. Recounting her experience of urinary incontinence as an inpatient after a seizure, Helen commented:

"they were all running in and out, so I think every member of my ward… saw me with this big wet patch and then they just left me to sleep on the sofa and didn't give me a blanket or anything, I just felt very exposed … and so that was pretty humiliating" (Helen)

Participants received cruel and judgemental comments, such as "*he's a right fool*" (Steve), having seizures referred to as "*weird shit*" (Sarah). Participants could sense people's

disgust in their body language: "*there is just that little look… and you just know what they're thinking*" (Steve), as though their seizures made them an object of disgust.

Notably, lack of understanding and compassion pervaded among healthcare professionals (HCPs). Poor treatment by HCPs was frequent, making participants feel they had "*feigned illness*" (Rachel) written in their record.

> *"I couldn't communicate that I needed the loo…So I managed to, like an eel slithering out of water, I managed to kind of flop off the bed onto the floor… I was pushing myself along with the knowledge inside of my body, trying to get the loo. And the nurses stopped me and they were kind of shouting at me*" (Rachel)

Rachel's comparison of herself to an animal illustrates the degradation she felt by her treatment. The comparison of herself to a disgust-evoking animal reveals the extent of her self-disgust in this instance.

Participants felt dismissed by HCPs due to having a functional condition. Consequently, participants were not given space and privacy - *"people were sitting around eating their lunch while I was having this mega attack and wetting myself"* (Helen) - as though they were not worthy of respect, which compromised their dignity. Such interactions made participants feel their suffering was disbelieved, provoking shame for their seizures. Some felt they should 'prove' (Grace) themselves, worsening their condition and reinforcing their sense of worthlessness and self-hatred.

> *"To have people telling you they don't believe you, or it can't be that bad, or get up off the floor. You just think, when it's reflected back at you, if it looks like a duck and it quacks like a duck, then it's a duck, isn't it? Yeah, so I am worthless, aren't I?"* (Rachel)

Ultimately, participants' feelings of self-disgust was interpreted as stemming from repeated experiences of revulsion by others, which then became internalised: *"I feel disgusted in myself, erm but in the eyes of other people"* (Steve).

3.2 Experiencing self-disgust as intense and inescapable

Self-disgust was experienced in two ways: as a strongly held, long-term, unchangeable belief, and as an intense emotional experience triggered by certain elicitors.

3.2.1 A chronic and unchangeable belief

Self-disgust was described as a feeling that ran deeper than hatred, a sense the body was innately bad or rotten: *"But it was when I thought about it, especially then like just how bad that it was, you know, I would always just be like 'oh I'm vile.' Vile seems to be the word"* (Kelly). Self-disgust was a constant, inescapable feeling that seemed to *"hang around like some hideous smell in the air"* (Rachel).

Some participants experienced self-disgust from early childhood. With this chronicity, self-disgust became enmeshed in their being: "*I don't see that it is that, I see that I am that*" (Grace). Thinking of themselves elicited repulsion and nausea *"When I think of me, I just think 'eugh'"* (Grace). As Lauren described:

> *"I feel like just sick… it's like I need to release but at the same time it makes me feel disgusting, like I feel sick. I hate myself, like I don't like that feeling"* (Lauren)

In these examples, the distinguishing feature of self-disgust was the association with revulsion and nausea, demonstrating the emotion's distinction from other self-conscious emotions such as shame or guilt.

Participants did not understand why others would want to be near them due to their disgusting nature, making them suspicious of those who did.

"I am so adamant that my body's bad, disgusting… it makes you think stupid things like 'is she just with you because of sympathy?'… There's that little bit in my head that can't give the hundred percent trust again." (Kelly)

Over time, self-disgust wore away at participants, leaving them struggling to *"find the good or the pleasure in anything"* (Kelly), to a point of hopelessness for a future without self-disgust.

3.2.2 An intense emotional experience

Self-disgust was also experienced as discreet, intense emotional episodes that were consuming, uncontrollable and frightening.

"it's like you're on a roller-coaster going downhill and you want to stop the rollercoaster but the rollercoaster's not in your control… you just feel like it's never gonna end" (Steve)

Self-disgust could manifest as intense anger and hatred at the self, a *"labyrinthine"* (Rachel) of feeling, thought and emotion, the intensity of which could lead to vomiting, seizures and wishes of death, as if death was the only escape from self-disgust: "*I end up in an extreme state where… I just want to end it"* (Sarah).

"I just get so annoyed, so frustrated, and so upset that I physically end up nearly throwing up because of how I feel about myself…you get emotionally worked up. And if you get too emotionally worked up you end up in a seizure." (Sarah)

For many, self-disgust led participants to intense self-criticism, where contempt for themselves could be heard in their voice. The intensity of the revulsion seemed to lead participants to lose respect for themselves, in a way distinct from shame or guilt, as demonstrated by Rachel's comparison to this disgust-evoking Stars Wars character.

"I'm stuck in this. I am doing this to myself. I am angry with myself. I hate myself. I am doing this to myself, it's just a kind of spiral of doom… I mean, look at the state I'm in! Look at me, this lump on the sofa, this Jabba the Hutt-like lump on the sofa who's pontificating at you [at interviewer]. This was never me!" (Rachel)

Participants could not look at themselves in the mirror due to the self-disgust elicited by their own image. For some, their reflection reminded them of their trauma, perpetuating self-disgust.

"if I did look in the mirror… all I could see was that, that trauma, massive like horrible-looking teenager" (Jane)

3.3. Understanding the relationship between self-disgust and FDS

All participants felt disgust for their FDS, following internal and external revulsion. Self-disgust in the context of FDS was felt on three levels: during seizures, for having a functional disorder and for having a life-altering, disabling condition. It also was felt to have a causative role in the generation of a seizure.

3.3.1 Seizures and self-disgust: A vicious cycle

During seizures, participants felt completely out of control, as if their body had been taken over by someone else, like a *"body snatcher scenario"* (Lauren). Some remained aware during seizures and felt they could *"see"* themselves, like an *"out of body experience"* (Steve), which elicited deep shame and revulsion for their bodies:

"I could see myself and how big and fat and ugly I looked with this big wet patch around my, you know… I'm throwing myself about, and I'm pulling funny faces and I'm clawing my hands up… I just felt disgusting, I just felt ugly, I just felt horrible" (Helen)

Two participants re-experienced traumatic events during seizures that played out *"like little tiny clips"* (Steve), provoking guilt, frustration and self-disgust:

> *"I was sexually assaulted by a stranger… and I always have that feeling* [during seizures]*…like someone's taken over my body and…I always, like get flashbacks"* (Lauren)

Participants' disgust for their seizures also emerged from feeling they were *"showing weakness when I'm trying to be strong"* (Kelly). The vulnerability elicited further disgust, as though the seizures revealed a private, shameful part of themselves.

Self-disgust during seizures was so intense, participants wished they could disappear: *"I just want the ground to swallow me up"* (Grace), and to *"curl up and die"* (Jane) as the feelings were too unbearable to live through. The intensity of the emotion was also considered strong enough to bring on a seizure: "*And if you get too emotionally worked up you end up in a seizure."* (Sarah)

3.3.2 Deviation from the medical norm: Disgust for FDS

Participants experienced difficulty accepting FDS. Rachel perceived FDS as a betrayal by her body which was deeply frustrating and provoked "*utter self-revulsion."* Some participants had doubted the legitimacy of their seizures "*because I didn't have that bit of paper or scan that showed other people 'look this is what's happening, I'm not making it up"*" (Kelly). They oscillated between acknowledging the legitimacy of their seizures and blaming themselves, as though their self-disgust always made a part of them believe they were "*doing it to themselves*" (Helen). This seemed to result from the external stigma for FDS: *"it affects me because of the shame of it, the stigma of it"* (Grace).

Knowing people who had died from epilepsy added "sheer guilt" for having FDS and compounded Helen's experience. Knowing "*they* [seizures] *won't harm*" her elicited self-disgust and perpetuated the stigmatising belief that her functional seizures were not legitimate.

> *"I just felt so disgusted that his seizures killed him. Mine won't kill me, how's that fair?... her beloved brother died of epilepsy and now her daughter's having seizures all over the place which aren't real. I know they are real but you know what I mean."* (Helen)

3.3.3 A drain and a burden: Self-disgust related to disability

Participants could not accept having a life-altering, disabling condition. Losing jobs that gave them purpose and which had "*offered something to the world*" (Rachel) made them feel like *"a drain on society*" (Sarah) and *"worthless"* (Helen).

Work provided protection from self-disgust. The resulting isolation from unemployment intensified self-disgust.

> *"you're just left with you, and it makes you question like so much… like what do you have to offer people…and it just makes you the person that you don't recognise anymore… you feel like you're on your own and your own worst enemy"* (Kelly)

Struggling daily with their disability wrecked participants' self-esteem. Thinking about their losses deepened their frustration and self-disgust.

> *"I can't stand being that way. It makes you feel useless…You feel disgusted that you can't do simple things like the weekly grocery shop by yourself because you might have a seizure"* (Sarah)

Feeling useless and incapable made them feel a burden and that they were "*letting everyone down*" (Helen), unworthy of receiving care from others.

> *"I hate that I'm imposing on him like that, yeah? Because, when he met me, I was capable. I was earning a decent salary…And now I'm dependent on him… it's awful for him. I don't want that for him. I want better for him."* (Rachel)

Participants felt so deeply disgusted with who they were, they could not accept themselves, and felt they deserved the experienced societal repulsion

3.4 Suppression and seclusion- attempting to cope with self-disgust

Some participants had positive methods of alleviating self-disgust, through therapy, maintaining hobbies or drawing on support from trusted relatives. However, most attempted to cope in ways that provided temporary relief but ultimately maintained self-disgust.

3.4.1 Avoiding exposure through social withdrawal

Most participants withdrew socially or ended relationships, feeling they were a threat to others: *"you worry about going in places because you consider yourself a health and safety hazard"* (Sarah). While this was partly purposed at protecting others from them, participants also sought to protect themselves from others' anticipated disgust: *"you don't want to do something that may put somebody else off"* (Steve).

Self-disgust also hindered participants' self-help efforts. For instance, Steve withdrew from psychological therapy as revealing his self-disgust was too unbearable: *"you don't wanna let him* [therapist] *in to see that disgust in you."*

The resulting isolation provoked loneliness and social exclusion, but the risk of exposing themselves to further external repulsion was too great.

"if I wanted to meet a new person… I think do I do it? Do I not do it? It's like no I don't wanna risk it, I don't wanna risk the hurt and the pain and the embarrassment." (Jane)

3.4.2 Emotionally suppressing the unbearable self-disgust

Most participants avoided their emotions to cope. For some, this required conscious effort: *"I will just pop the lid back on and then erm maybe get ridiculously drunk"* (Helen). For others, emotional avoidance was an automatic dissociative process: *"you don't realise you're doing it"* (Jane). During interviews, participants displayed avoidance through avoiding answering questions or referring to self-disgust in past tense, as the concept was too painful to connect with in the present.

Some participants had chronic patterns of emotional *"suppression"* (Lauren), putting on a *"front"* (Grace) to convince others, and themselves, they were coping: "*no one would be able to tell* [self-disgust] *was a problem*" (Grace). This functioned both as self-protection from self-disgust, and to protect others: *"I've kind of trained myself to do it from a really young age so that people don't worry about me"* (Lauren).

However, emotional avoidance was ineffective, and self-disgust would eventually resurface or worsen: "*then all the little stupid things become like a big thing"* (Steve). Some felt emotional avoidance predisposed FDS, adding another layer of emotional difficulty as self-disgust and FDS perpetuated each other.

"I honestly do feel like that's why I have the seizures now, but then they bring… [self-disgust] *to the forefront and then it's, it's like a cycle, a constant cycle."* (Lauren)

3.4.3 Physically hiding oneself to deny the reality of self-disgust

For some, covering mirrors or wearing ill-fitting clothes temporarily allowed them to deny how they presented to the world, providing relief. Participants' reflections reminded them of how they and their bodies changed through having FDS, eliciting further disgust.

"I can't stand to look in the mirror because it makes me feel sick of the way I've ended up with seizures and the way they're affecting me every day" (Sarah)

Attempting to hide their bodies with clothes seemed to serve as protection from further disgust responses. For instance, Jane wore baggy clothes *"cos I didn't want people looking at me."* Eventually, these methods failed to provide protection, as participants would inevitably be faced with their image again, continuing the cycle of self-disgust

4. Discussion

The aim of this first study on the subjective experiences of self-disgust in pwFDS was to provide an in-depth interpretative account of this self-conscious emotion. Of the 108 participants who completed the SDS, 85.2% scored above the level previously established as indicating high levels of self-disgust in clinical samples, with the overall mean score being 52, suggesting self-disgust is relevant in many pwFDS. Four GETs were identified; 'understanding the origin of self-disgust as based in rejection', 'experiencing self-disgust as intense and inescapable', 'understanding the relationship between self-disgust and FDS' and 'suppression and seclusion - attempting to cope with self-disgust'.

The findings regarding historical trauma as a predisposing factor for self-disgust align with the idea of self-disgust as an emotion schema, developing in childhood as a result of trauma and abusive familial relationships [27]. It is also consistent with ideas around the self still being 'contaminated' years after a traumatic or abusive event [48]. The study's finding that self-disgust began in some participants' formative years also resonates with previous

research indicating that other self-conscious emotions, such as shame, emerge around the age of three [49]. Additionally, humiliation from shame and disgust-based bullying may have created a sense of inferiority to others, previously found to increase self-criticism and self-disgust in individuals with depression [50]. Participants who disclosed sexual trauma felt perpetually contaminated, suggesting an internalised disgust response [51], a common predisposing factor in FDS, along with emotional abuse and family dysfunction [52]. This also resonates with the idea of disgust as an "essentialising emotion", i.e. where disgust becomes part of the essence of the entity (in this case the self) that is deemed disgusting (e.g.,53). This also makes disgust difficult to modify, potentially contributing to the chronicity of self-directed disgust in the current population [53].

FDS is a highly stigmatised condition [14]. Stigma can promote disgust and result in social rejection [54], contributing to the promotion of negative self-conscious emotions, including self-disgust [19,27]. Participants' reported experiences with HCPs in the current study are similar to those in previous studies where participants endured abusive behaviours from HCPs, resulting in trauma and avoidance of medical care [13]. This study also highlights the personal cost of this rejection, as participants internalised negative reactions, resulting in feelings of worthlessness and self-disgust, similarly to how people with epilepsy internalised the negative reactions of others in Mayor and colleagues' [26] study.

The pervasive nature of self-disgust has previously been similarly described (e.g. 26). Again, while ever-present, self-disgust could be intensified by elicitors such as the participant's own physical reflection. As a discrete emotional experience, self-disgust had a corporeal quality, and was experienced viscerally, stimulating nausea and vomiting, suggested to be a disgust-based rejection of the self [55].

Results also suggest a direct association between self-disgust and functional seizures themselves, consistent with the idea that emotional overwhelm can elicit FDS [4,56]. Participants also made a link between their self-disgust, hopelessness and increased suicidal ideation, which is highly prevalent in individuals with FDS [57] and known to increase risk of suicide [58]. Moreover, self-disgust has previously been shown to increase the risk of suicide [59], demonstrating the seriousness of self-disgust to emotional wellbeing.

Interestingly, findings suggest a complex, bi-directional relationship where self-disgust triggered seizures, but FDS also exacerbated self-disgust. This relationship is similar to the conceptualisation of shame's role in the onset and exacerbation of FDS [16]. FDS could be considered to serve a protective function from unbearable and overwhelming internal and external stimuli, including self-disgust, providing relief by facilitating escape (dissociation) from consciousness and the body. However, rather than providing relief, participants' disgust for and during seizures means FDS may add another dimension to, and exacerbate, self-disgust [16].

Participants' revulsion for their disability may also indicate internalised ableism, where societal prejudice about disability becomes internalised [60]. For example, Sarah's comments about feeling like '*a health and safety hazard'* indicate the internalisation of phrases used to blame the individual for structural barriers [61]. In the current study, participants' self-disgust is theorised to stem from their difficulty maintaining capitalistic cultural standards of economic competence and productivity through employment and independence, shown to negatively impact on self-esteem and confidence [34,62,63]. Unconscious, internalised messages about disabled people as 'other' and disgusting, as seen in participant quotes, may also contribute to this [63]. Congruently, participants valued their previous employment, which served to protect them from self-disgust, the loss of which exacerbated negative self-directed feelings [64].

Emotional suppression and avoidance is also reported in FDS [65,66]. Avoidance or suppression of self-disgust could be considered a rejection of the self. Indeed, studies show people with high levels of self-disgust attempt to dissociate or cognitively avoid the 'disgusting' parts of the self [67]. Participants also denied the presence of self-disgust, as though acknowledging the emotion was inherently threatening to the integrity of their personality [55]. Similarly, covering mirrors to conceal themselves could be further evidence of denial or dissociation [55]. Suppressive strategies provided only temporary relief for participants. In fact, expressive suppression has been shown to play a predictive role in the expression of self-disgust [68] and emotional avoidance perpetuates difficulties associated with poorer quality of life [69].

The current study's findings are similar to Mayor and colleagues' [26] study on self-disgust in epilepsy. Participants in their study felt betrayed and disgusted by their body and vulnerability. To cope, participants would avoid situations that risked eliciting self-disgust and distanced themselves from relationships [26]. In both studies, self-disgust is directly related to the experience of seizures and negative reactions of others. While the small scale of both studies limits direct comparisons between the two patient groups, epileptic and dissociative seizures are both stigmatised and linked to self-disgust although epilepsy does have the status of a recognised neurological disorder [70]. Given the closer link between trauma and FDS, and the increased tendency of pwFDS to dissociate [71], pwFDS might have a more critical self-perception, suggesting self-disgust could be a greater issue for this patient group.

4.1. Strengths, limitations and future directions

This was the first study to explore the unique lived experiences of self-disgust in pwFDS. IPA, an in-depth qualitative methodology, enabled the elicitation of vivid and

emotive accounts which confirmed the pervasive presence and significant influence of self-disgust in participants' lives. While IPA typically involves small sample sizes, which are sometimes criticised for lacking generalisability, this critique stems from a misunderstanding of qualitative research paradigms. Generalisability, as traditionally understood, is a criterion from quantitative research and is not central to the evaluation of qualitative studies [72,73]. Instead, qualitative research prioritises depth, contextual understanding, and idiographic focus – as seen in these results.

While the remarkably high prevalence of self-disgust reported in this study suggests self-disgust may be relevant for many pwFDS, this may be an overrepresentation of the true prevalence of self-disgust in this population. Our interviewees were recruited explicitly from the highest scorers on the SDS and are therefore not typical of the whole patient group. Even the high self-disgust scores across the group may the result of sampling bias as the transparency of study recruitment materials possibly attracted a subset of pwFDS who experienced self-disgust and had an interest in discussing this. However, while exploration of the quantitative findings from the screening questionnaire goes beyond the scope of this study, further research to explore statistical correlates – or moderators of the relationship between self-disgust and other facets of mental health (e.g., 74) - would be useful. Having said that, it would be challenging to distinguish clearly between the association of FDS themselves or of so-called psychiatric and physical "comorbidities" of FDS with self-disgust, as FDS are often so intimately linked with another condition (such as PTSD or panic disorder) that the effects of seizures may not be readily separable from those of the broader illness experience. While some quotes indicated that the participants felt the self-disgust was directly related to FDS, as opposed to their other difficulties, a contribution made by other difficulties remains an unacknowledged possibility. This was a cross-sectional study and all of the ideas discussed suggesting temporal and causal relationships between FDS and self-

disgust are hypotheses which could be examined in future longitudinal studies. Such longitudinal designs are being increasingly used with IPA and can provide an in-depth account of changes in the phenomenon in question over time [75].

5. Conclusion

This study highlights the relevance of self-disgust in a significant subset of individuals with pwFDS chosen because of their self-reported high levels of this emotion. IPA analysis revealed the strong, pervasive influence of self-disgust on participants' emotional and behavioural functioning. Although participants described coping strategies that offered temporary relief, these often reinforced and maintained the underlying cognitive-affective state. Self-disgust may represent an underrecognised barrier to psychological engagement and treatment responsiveness in pwFDS, despite evidence supporting the effectiveness of psychological interventions for both seizure and non-seizure symptoms in this population. It is therefore important to assess for the presence of self-disgust in clinical settings and to offer additional support around engagement and therapeutic alliance development, particularly for individuals for whom self-disgust is a salient issue.

While our small sample study does not allow for definitive recommendations on the most suitable therapy types, it is possible to speculate on the mechanisms involved in the generation and maintenance of self- disgust and therefore what could be targeted therapeutically. Reducing shame, for example, through encouraging more self-compassion could be useful [76] so psychotherapeutic models that explicitly target self-critical and shame-based emotions - such as Compassion-Focused Therapy (CFT) - may be particularly beneficial [77]. This is not to rule out other therapeutic approaches which could also be useful [78,], particularly if they address other implicated mechanisms such as problems in emotional processing [79]. Additionally, existing therapeutic approaches may require

adaptation to address self-disgust as a potential impediment to meaningful psychological change [32]. Given the identified link between trauma and both self-disgust and FDS [80] in a subset of individuals, considering trauma-informed approaches when working with such populations more generally could also be useful [81, 82]. Given empirical research linking stigmatised conditions to disgust or disgust-based reactions [83], while often outwith the remit of individual clinicians, more societal-focused approaches to reduce the stigma associated with FDS are also recommended [84].

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Supplementary Appendix 1

Participant Representation Matrix

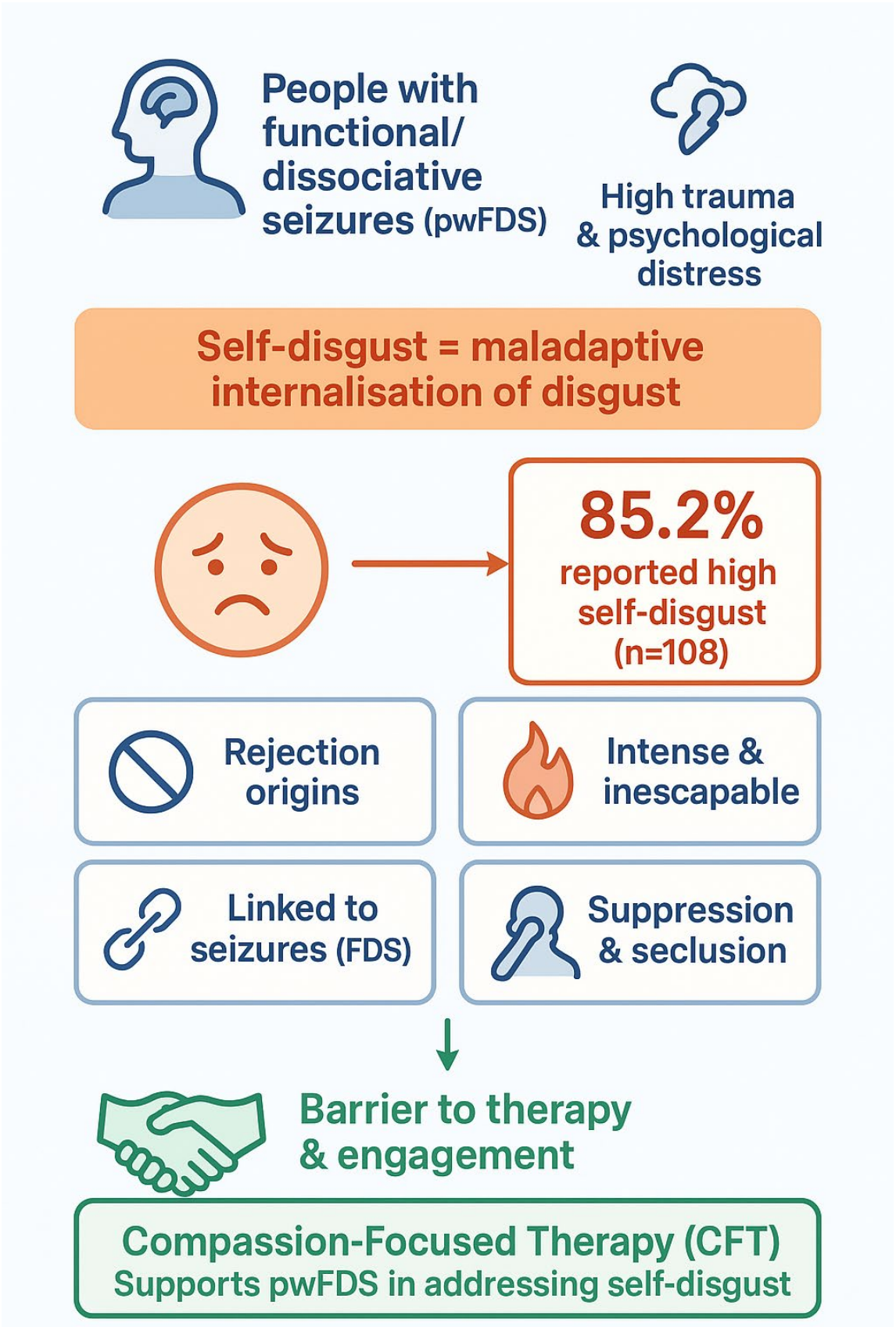
	Grace	Sarah	Jane	Rachel	Steve	Lauren	Helen	Kelly
Understanding the origin of self-disgust as based in rejection								
Historical abuse laying the foundation for self-disgust	SD originates from early trauma	Negative self-concept results from complex trauma	Disgust and avoidance from others perpetuates SD Feeling of inferiority significant precursor to SD			Negative experiences with others promotes worthlessness and SD	Experience of SD as constant, uncontrollable criticism Disgust at what she looks like during a seizure	Negative experiences with others fuels self-blame and inner critic
Others' repulsion introducing shame and disgust for FDS	Social rejection perpetuates feelings of worthlessness	Internalising others' negative responses/reactions/behaviours Stigma of FDS is an enabler of self-disgust	Disgust and avoidance from others perpetuates SD	Stigmatising experiences perpetuates feelings of worthlessness and SD	Others' disgust triggers SD	Negative experiences with others promotes worthlessness and SD	Rejection and humiliation-experience with others during seizures	Negative experiences with others fuels self-blame and inner critic
Experiencing self-disgust as intense and inescapable								
A chronic and unchangeable belief	SD is experienced viscerally	Feeling overwhelmed by the physical and emotional nature of SD	SD experienced as belief and	SD is constant and self-perpetuating	SD described as intense, self-perpetuating and	No sense of personal identity forges self-hatred	Experience of SD as constant, uncontrollable criticism	Disgust at own body SD is worse

			emotional experience		uncontrollable	SD as perpetual self-hatred cause self-neglect		than self-hatred
An intense emotional experience	SD makes them feel sub-human SD is experienced viscerally	SD entwined with other negative emotions Feeling overwhelmed by the physical and emotional nature of SD	Vulnerability as an elicitor of SD SD experienced as belief and emotional experience	SD is constant and self-perpetuating	SD described as intense, self-perpetuating and uncontrollable	SD as perpetual self-hatred cause self-neglect		SD is worse than self-hatred Disgust at own body
Understanding the relationship between self-disgust and FDS								
Seizures and self-disgust: A vicious cycle	Unbearable shame of having functional seizures	Understanding seizures and SD as a vicious cycle	SD creates shame and disgust for seizures Vulnerability as an elicitor of SD Disgust and avoidance of others		Seizures elicit SD-disgust for his vulnerability	Negative experiences with others promotes worthlessness and SD Lack of control of body during seizures trigger SD	Disgust at what she looks like during seizure Rejection and humiliation-experience with others during seizures	Disgust at own body Disgust for self during seizures

			perpetuates SD (quotes from p20)					
Deviation from the medical norm: Disgust for FDS	Unbearable shame of having functional seizures			Revulsion for her disability	Seizures elicit SD-disgust for his vulnerability	SD creates shame for seizures SD as perpetual self-hatred cause self-neglect Lack of control of body during seizures trigger SD	SD for having functional seizures	Disgust at own body Negative experiences with others fuels self-blame and inner critic
A drain and a burden: Self-disgust related to disability		SD entwined with other negative emotions Internalising others' negative responses/reactions/behaviours		Revulsion for her disability SD makes her feel unworthy of receiving care Self-disgust is constant, and self-	Seizures elicit SD-disgust for his vulnerability	SD as perpetual self-hatred cause self-neglect	SD makes her feel and burden and let down Disgust at what she looks like during seizure	Loss from FND gives rise to SD

				perpetuating				
Suppression and seclusion- attempting to cope with self-disgust								
Avoiding exposure through social withdrawal	Withdrawal - protecting self and others from disgust	Withdrawal- a mechanism of protecting self and others	Avoidance and withdrawal - protection from the disgust	Revulsion for her disability	Withdraws to protect self and others from disgust	SD as perpetual self-hatred cause self-neglect		Disgust for self during seizures
Emotionally suppressing the unbearable self-disgust	Total disconnection from own being because of SD Self-disgust makes them feel sub-human	Difficulty engaging with the idea of SD Negative self-concept results from complex trauma	Dissociation from the unbearable SD Avoidance and withdrawal - protection from the disgust	Revulsion for her disability	Tries to block out SD to protect himself from it	Detachment - coping with the unbearable feeling of SD No sense of personal identity forges self-hatred Lack of control of body during seizures trigger SD	Experience of SD as constant, uncontrollable criticism	
Physically hiding oneself to deny reality	Self-disgust is experienced viscerally	Becoming invisible- protecting against the toxicity of the self	Attempting to be invisible to protect					Disgust at own body

of self-disgust	from the disgust


People with functional/ dissociative seizures (pwFDS)
High trauma & psychological distress
Self-disgust = maladaptive internalisation of disgust
85.2%
reported high self-disgust (n=108)
Rejection origins
Intense & inescapable
Linked to seizures (FDS)
Suppression & seclusion
Barrier to therapy & engagement
Compassion-Focused Therapy (CFT)
Supports pwFDS in addressing self-disgust

Highlights

- This study is the first on self-disgust in pwFDS using a qualitative method.
- Themes highlighted self-disgust's origins, its intense experience, its relationship, including a potentially causal one, with seizures, and coping mechanisms.
- Self-disgust should be assessed during initial consultations.
- Psychological interventions may be helpful to support pwFDS' experience of self-disgust.
- Multi-level awareness campaigns on FDS are needed to increase awareness and reduce stigma.