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Review

Shame in the treatment of patients with psychogenic nonepileptic seizures: The elephant in the room

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ABSTRACT

Previous research has established a link between psychogenic nonepileptic seizures (also known as dissociative or functional seizures) and abnormal emotion processing. In a companion article to this multidisciplinary narrative review, we have argued that, in the context of a biopsychosocial understanding of the condition, the emotion of shame is particularly likely to contribute to the aetiology, manifestation, semiology and perpetuation of psychogenic non-epileptic seizures (PNES). Here we demonstrate how unrecognised and unaddressed shame may cause difficulties when clinicians explain the diagnosis, attempt to engage patients in psychological treatment, construct a diagnostic formulation and undertake psychotherapy. Case vignettes are used to bring theoretical considerations to life and to illustrate the complex interactions which may be observed between high shame proneness, chronic and dysregulated shame, stigma and PNES. The particular focus on shame does not mean that recent explanatory models of PNES are obsolete. Rather, we demonstrate how the inclusion of shame helps to embed the emotional, cognitive and behavioural aspects of the Integrative Cognitive Model (ICM) of PNES in a social / interpersonal context. While we describe how a number of different psychotherapeutic approaches can help to address shame-related processes we conclude that specific modalities are less important than the eventual enhancement of emotional literacy and tolerance through a healing relationship with the psychotherapist.

1. Introduction

In the first of this two-article series, we have argued that excessive shame proneness and the dysregulation of shame may be a particularly common emotional link between psychiatric “comorbidities” and PNES [1]. We have also demonstrated how shame may trigger PNES and how shame (its avoidance or secondary emotions aroused by shame) could contribute to how the episodes present. Shame can also be relevant for patients’ thoughts, feelings and behaviour in the interictal state. This means that shame may affect a patients’ journey after the diagnosis has been made – i.e., how they respond to the

explanation of their seizure disorder, how easy they find it to engage in psychological treatment, accept a psychological formulation of their condition, participate in therapeutic activities and sustain gains at the end of therapy. Furthermore, if shame is as relevant in to the aetiology of PNES in as many patients as we suspect, excessive shame proneness and dysregulation may be important treatment targets. This paper complements our narrative review of the development and maturation of shame perception and regulation and its relationship with PNES. It focuses on the potential effects of shame in therapeutic encounters by tracking patients’ treatment journeys. Case vignettes (deidentified, blended and modified to protect patient privacy) are used to bring the

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1st Revision

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treatment challenges associated with shame to life.

2.0 Communication of the diagnosis and engagement in psychological treatment

Shame can make it difficult for some patients to accept an explanation which casts PNES as a psychological condition, and may elucidate why explanations may be provided so delicately by diagnosticians that they confuse patients or leave them none the wiser about the nature of their seizures [2,3]. Nearly all patients with PNES report shame about a disorder that is perceived by others (and sometimes by themselves) as: a) “not real, serious, or valid,” b) possibly “feigned” for alternative purposes (e.g., “drug seeking,” “attention seeking”) or c) seemingly “voluntary” [4,5]. In any of these scenarios, patients are cast as **responsible** for their condition. This feeling of responsibility is particularly likely to cause patients to feel flawed or abnormally weak when they experience that they cannot control their seizures [6], despite being told by others (or thinking themselves) that they should be able to exert this control [7,8]. The discrepancy of expectation and perceived reality can be a potent cause of shame, frustration and anger.

Furthermore, when the patient is informed that PNES is a manifestation of a “mental” disorder, they may experience the shame and stigma associated with any psychological or psychiatric condition [9,10]. This shame may still be felt when psychiatric disease labels are delicately avoided (for instance through the exclusive use of “non-”-labels, as in “non-epileptic” seizures), communicating to the patient that theirs is a dispreferred condition that is less real, less acceptable or more embarrassing than one that can simply be named [11]. A rapid discharge from the neurology service with a vague referral recommendation to psychiatry may enhance the feeling of being taken less seriously than a patient with a “proper medical disorder” and interact with the sensitivity to abandonment which characterizes a substantial subgroup of patients with PNES disorders [12] (see Case 1).

Furthermore, the communication of the diagnosis can lead patients with traumatic histories to realize that there may be an association between shameful events in their past and their PNES – memories of such events may be reactivated during the diagnostic process [6,13]. Shame which may already have been felt before the diagnosis of PNES was formulated may be aggravated if patients are made to feel exposed during the explanation of the disorder and then abandoned (Case 2).

Patients may also experience shame associated with the seizure semiology itself as it could be perceived to display private and embarrassing details (Case 3).

Many individuals who have been traumatised (especially but not exclusively in early life) find it easier to exert a degree of control over their traumatic experience by blaming themselves rather than the aggressor for the acts committed against them [14]. This is particularly likely to happen if the aggressor is also a caregiver and therefore, for self-preservation’s sake, must not be seen as someone who would endanger the victim’s survival. In fact, those two characterizations of the caregiver are incompatible. While this construct may help victims foster survival through their vulnerable childhood years, it is likely to leave them feeling chronically guilty (and ashamed) about the trauma

because they feel responsible for experiencing it [15]. This process has been described previously: “By developing a contaminated, stigmatized identity, the child victim takes the evil of the abuser into herself and thereby preserves her primary attachments to her parents.....Adult survivors continue to view themselves with contempt and to take upon themselves the shame and guilt of their abusers. The profound sense of inner badness becomes the core around which the abused child’s identity is formed, and it persists into adult life.” [15]. The perpetrator-victim role reversal may not only stop patients from accepting any explanation of PNES as a consequence of trauma, this role-reversal may also stop them from engaging in treatment and risking the uncovering of their “terrible secret”.

2. Shame as a cause of difficulties with initial engagement in psychological treatment

Shame may also pose a hurdle to engaging in psychological treatment in a number of ways. Even in the absence of perpetrator-victim role-reversal, the awareness of traumatic but shame-associated experiences may stop some patients from attending their initial session of psychotherapy because it feels dangerous, there seems to be a risk of losing control or being consumed in some way if their profoundly shameful secret is exposed. When such patients present for therapy, they may come across as ‘**reserved**’, seem unable to offer any reasonable explanation for their PNES, and report an almost absolute absence of stress or psychiatric history. It is not unusual for some patients presenting in this way to disclose after many weeks or months of psychotherapy (if treatment has lasted that long) a never before discussed experience which is shameful in nature (Case 4).

Other patients may lack a self-perception of stress or mental health symptoms in their current lives and experience shame at taking up clinicians’ valuable time. This type of shame is most likely to be experienced by patients whose emotional needs have not been met in their early childhood. This neglect may have resulted from parental overwhelm, such as when parents had to care for another ill sibling or had to deal with paternal or maternal depression or anxiety. The lack of care taught these patients to try and cope, ‘get on with things’ and to ignore their emotions. This kind of early life experience fosters feelings that the needs that were viewed as unacceptable by the caregivers are indeed unacceptable and selfish, so anytime a need emerges it is accompanied by shame [16].

More specifically, difficulties with the engagement in psychological treatment can often be related to an unawareness of chronically high levels of shame. In some cases, individuals experiencing such high levels of shame think: “I am weak, stupid, not good enough, useless” etc.. They perceive these self-accusations as fact rather than a reaction to a particular shame-inducing trigger or situation. Although their seizures may be triggered by the emergence of intense emotions (including shame), the subjective seizure experience of these patients is likely to be of going blank or numb, thereby avoiding the link between the seizures and emotions. Indeed, the experience of acute shame could be viewed as being on a continuum from perceived shame at the milder end to dissociation or “going blank” and more dramatic seizures at the severe

Case 1: The shame and stigma felt when diagnosed with a psychological condition.

Upon receiving the diagnosis of PNES in the epilepsy unit, a young woman reported an intense feeling of shame because her family would now see that the years spent visiting specialists had been wasted since she “just had a psychological problem.” In addition, the doctors seemed to be “dancing around” the diagnosis, never actually giving it a name. She perceived that the doctors seemed to want her out of the hospital as soon as possible. They seemed uncomfortable which led her to suspect that they felt that she “really did not have anything serious (i.e., epilepsy)” and was a nuisance. In fact, she admitted that, on some level, she had wished to have a recognized disease such as epilepsy and when she discovered she did not, was crestfallen and then further ashamed about this reaction.

Case 2: The shame of trusting a professional with an intimate memory only to be quickly discharged.

On the epilepsy monitoring unit, a Hispanic woman in her 30's recalled and shared with the neurologist her childhood sexual abuse (which she thought she had overcome). She was surprised to realize that this might be playing a role in her new onset seizures. She had not spoken about her history before to anyone, and it had been hard to tell the doctor about the abuse. To her surprise and dismay, later that day, she was discharged with a vague recommendation from the unit nurse (not the doctor) to "find a psychotherapist". She felt confused and ashamed by this response to her intimate disclosure and decided not to follow up. Nearly 8 years later, she finally arrived in a psychotherapist's office.

Case 3: How shame related to the public manifestations of PNES may activate additional seizures.

To most observers, a 19-year-old girl's episodes seemed to represent a rape and her attempts to protect herself. Her seizures occurred on a daily basis, in the presence of many of her friends (but also people she had never met before). She was admitted to an emergency unit with nearly continuous seizures. Between convulsive episodes, she was able to share that she had been raped by her grandfather at the age of 9 years and repeatedly after that until she left the home at 16. Unfortunately, she found herself caught in a bind; recalling any aspect of the rape triggered her PNES, but to her distress, she was aware that the seizures themselves seemed to demonstrate to the world what had happened to her (although she wished to keep it hidden). Non-epileptic status could be seen as stemming from this bind.

Case 4: When shameful memories feel too dangerous and can stymie treatment progress.

A 42-year-old woman with a complex medical history had worked with a psychotherapist for two years examining the effects of stress and day-to-day events on her PNES. She admitted to childhood trauma and had been raised by a neglectful mother, but she felt she had overcome it. Her seizure frequency remained unchanged. One day, when discussing her youth, she began to share a horribly traumatic and shameful rape that she endured when she was 19 years old. She had never told it to anyone and had a seizure while retelling it. This memory evoked intense shame, fury and sadness and later, she explained, had felt "too dangerous" to speak about. Treatment shifted to focusing on this experience and after a few months, her PNES had remitted considerably.

end. Cognitively, patients who "go blank" or have seizures of this nature may use strategies of attacking, rationalizing, raging or self-righteousness to avoid the feeling of shame [17]. The rapid burying of shame (and other strong emotions including unexpressed rage) and its cognitive processing may help to explain why alexithymia is observed in many patients with PNES [18]. Moreover, because shame and other intensely uncomfortable emotions are out of the person's awareness, it is difficult for them to understand how psychological treatment could possibly help.

The opposite patient presentation can also prove problematic: the patient who overshares. Here, shame may underpin a completely different problem complicating the longer-term engagement of a patient in a psychotherapeutic process, although, superficially, this is less evident. The *'emetic'* patient will detail multiple terrible and humiliating lifetime events in the first session. This logorrhoea seems to suggest that this patient is not blocked by shame and is open to making use of therapy, but often, such patients fail to return for the second session (perhaps because the therapist and the office are now tainted). A patient who does return also may paradoxically retreat from any meaningful discussion of the shameful events they initially shared. A seasoned therapist will know to intervene diplomatically and help the patient pace and explore these disclosures.

However, it is not only the patients' relationship with shame that can affect treatment engagement; the psychotherapist's responses to shameful content may be equally important for successful therapeutic connection. Any equivocal responses (e.g., exhibiting disgust, seeming overcome by the content, appearing rejecting, judgmental or dismissive) may result in the patient's silence about this content and can result in premature treatment termination. In addition, because witnessing the shame of another can be shame-inducing in some sense, the clinician

may feel conflicted about pointing out this emotion, which communicates nonverbally that this content must remain unspoken [19]. Useful resources for clinicians who work with patients with histories of extremely shameful indignities and humiliations include receiving clinical supervision and attending regular psychotherapy.

3. Identification of shame in psychological assessments / production of treatment formulations

It can be challenging for the clinician to detect a patient's shame in the first meeting. This is partly because there is "shame in revealing shame". In view of its particular interpersonal dimension, shame is harder to share with another than other somewhat less intolerable emotions (e.g., anger, sadness). However, it is important to identify shame (and guilt) even if they are masked by more prominent symptoms (for instance, anger, anxiety, symptoms of depression, PTSD, or obsessive-compulsive disorder), as delayed identification can stall therapeutic processes, impede emotional processing and reduce treatment effectiveness overall. In the context of psychiatric "comorbidities", excessive shame or shame dysregulation may represent the link between a heterogeneous range of mental disorders (including those listed above) and PNES, so failure to recognize this emotional link may impede the development of a comprehensive understanding of a patient's presentation.

Whilst being assessed - whether by therapists or neurologists - patients often emphasise their lack of control over what is happening in their seizures. While they truthfully report their subjective experience, the emphasis on this point may also demonstrate the patients' quest to be exonerated from responsibility, blame and their perception of some level of shame. The skill in therapy is to help such patients to explore

what might have led to the development of seizures, build awareness of physical cues of hyper- or hypo-arousal and help learn to recognize feelings and to self-regulate more effectively. However, it is essential to acknowledge that the therapeutic process can leave patients facing a dilemma: in gaining a better understanding of themselves and developing ways to manage their symptoms/life they begin to take ownership for their well-being. This process may trigger shameful feelings that they should have been able to do this earlier and without help ('If I can manage it now, why couldn't I always manage it?'). Treating shame requires gradual, repeated work, largely because of the pre-verbal conditioned sense of self that creates it (Case 5). Shame is often evoked by the process of being in therapy 'If I were adequate I would already know this.' Or 'I am weak and useless for needing to be here.' These thoughts often echo the belief about the original trauma: 'I should have been able to stop or avoid it.'

The discussion of these situations in psychotherapy activated a recollection of being shamed by her mother for wetting the bed as a child (aged 7–9). She felt as little control over her body now as she had when she had been criticized for not being able to control her bladder at night. She internalized her shame and the belief that she should be in control of her body and her emotions regardless.

In individual psychotherapeutic case formulations shame avoidance, high shame proneness and dysregulation may feature as predisposing, perpetuating and precipitating factors for PNES disorders. Although shame may not have been specifically named in previous studies of aetiological factors in PNES, it could, plausibly, be an important association of previously published potential contributors - including sexual and non-sexual trauma, bereavement, family dysfunction, bullying or other health problems. Indeed, a small study linking family dysfunction and trauma with "unspeakable dilemmas" or a larger study identifying degrading role changes as relevant aetiological factors hint strongly at the relevance of shame [13,20,21].

Dysregulated shame related to earlier experiences could help to explain why a later, apparently quite minor trauma is often reported just prior to the onset of a PNES disorder [22]. In the Integrative Cognitive Model (ICM) framework of PNES, shame experiences may shape the seizure scaffold and act as an internal cue triggering seizures [23]. Shame may also contribute to elevated levels of arousal and compromise inhibitory processes thereby reducing shame tolerance and making it less likely for individuals to manage potential PNES triggers with alternative cognitive or behavioural responses. Each seizure experience may be shame-inducing and make subsequent activations of the seizure

scaffold more likely by further elevating chronic shame levels. In view of the fact that many shame experiences are likely to arise in interpersonal scenarios, shame can provide an important link between this intra-individual cognitive model and patients' social environment (see Fig. 1).

Similarly, the concept of PNES and shame can be understood through models that conceptualize PNES as fuelled by dysfunctions at the level of arousal tolerance and cognitive-emotional information processing. In other words, from Baslet's pathophysiological model, it might be understandable that an emotion as intolerable as shame in someone with unstable cognitive-emotional-attention systems can represent a predisposing, precipitating, and perpetuating factor of PNES [24].

4. Treatment of patients with PNES and high levels of shame

The most appropriate treatment of shame-related mechanisms in patients with PNES will depend on an individual patient's circumstances, the contribution shame may be making to the patient's PNES disorder and its context. Cultural issues must also be considered in this respect [25].

In relation to childhood trauma, shame protects against the devastating reality that the child's caretakers are not always safe or trustworthy (Case 6). The child telling her/himself that the attacks occur because "I am bad", is preferable to the terrifying reality that the child has no control over the adult's unpredictable behaviour and is permanently at risk.

This shame leads individuals with PTSD to hide its source (rather than verbalise it), and, in extreme cases, to escape the pain through dissociation and even suicide. Similarly, it may have a deleterious role in patients with PNES with a significant trauma history, impeding verbalization and communion with the clinician. The protective efforts to avoid shameful content (e.g., traumatic recollections, secondary psychiatric symptoms, and even poor self-image associated with PNES itself) may not allow trauma and the associated emotions to be processed because access to social support ("no one must ever know") and any form of corrective learning experience (e.g., "I can tolerate intense emotions, no harm comes to me") is inhibited.

To attain sustained benefit from psychotherapy, paced disclosure of the shameful content is likely to be essential and regardless of preferred treatment modality. Patients burdened by shameful experiences will benefit from an accepting and non-judgmental psychotherapist who allows them to feel safe enough to share these experiences. Shame

Case 5: The shame of "failing" to hold off breakthrough seizures.

A female in her mid-fifties developed PNES two years prior to starting psychotherapy. She was unaware of a precipitating event for her seizure disorder and had no warning of her seizures. The seizures involved sudden collapse, and she had acquired so many injuries that she was very anxious and did not go out unaccompanied.

During the initial psychotherapy assessment, she reported a happy childhood and was unaware of any experiences, which could have put her at risk of developing PNES. On exploration it emerged that her younger sister was born with physical and mental disabilities and that her mother had been quite preoccupied with caring for her sister. Even after her sister was placed in residential care, their weekends were taken up with visiting her sister, and little consideration had been given to her own needs or interests. She perceived her mother as extremely critical of her.

She was very rational and had limited awareness of her feelings. Psychotherapeutic work on increasing bodily awareness and her ability to tolerate discomfort using grounding strategies allowed her to notice that she was more on edge than she had realized. While these strategies, alongside a better understanding of the relationship between her early life experiences and her symptoms, seemed to lead to longer periods of seizure-freedom, such periods made her increasingly anxious about when her next seizure was going to happen. Each new seizure would give her a sense of personal failure. To her, the fact that she could control her seizures to some extent meant that she should have been able to stop them - even before she had therapy. She also worried that her family and friends would blame her if she had a seizure for 'not doing her exercises'. She was harshly self-critical and feared that others would be similarly harsh. In psychotherapy she noticed how her seizures were on a continuum with blank spells, which she described as 'not being in the room'. They tended to happen during low level stress situations, for instance when she felt criticized by her husband for forgetting household tasks. Her sense of shame associated with realizing such minor failings fuelled the process and made blank spells more likely.

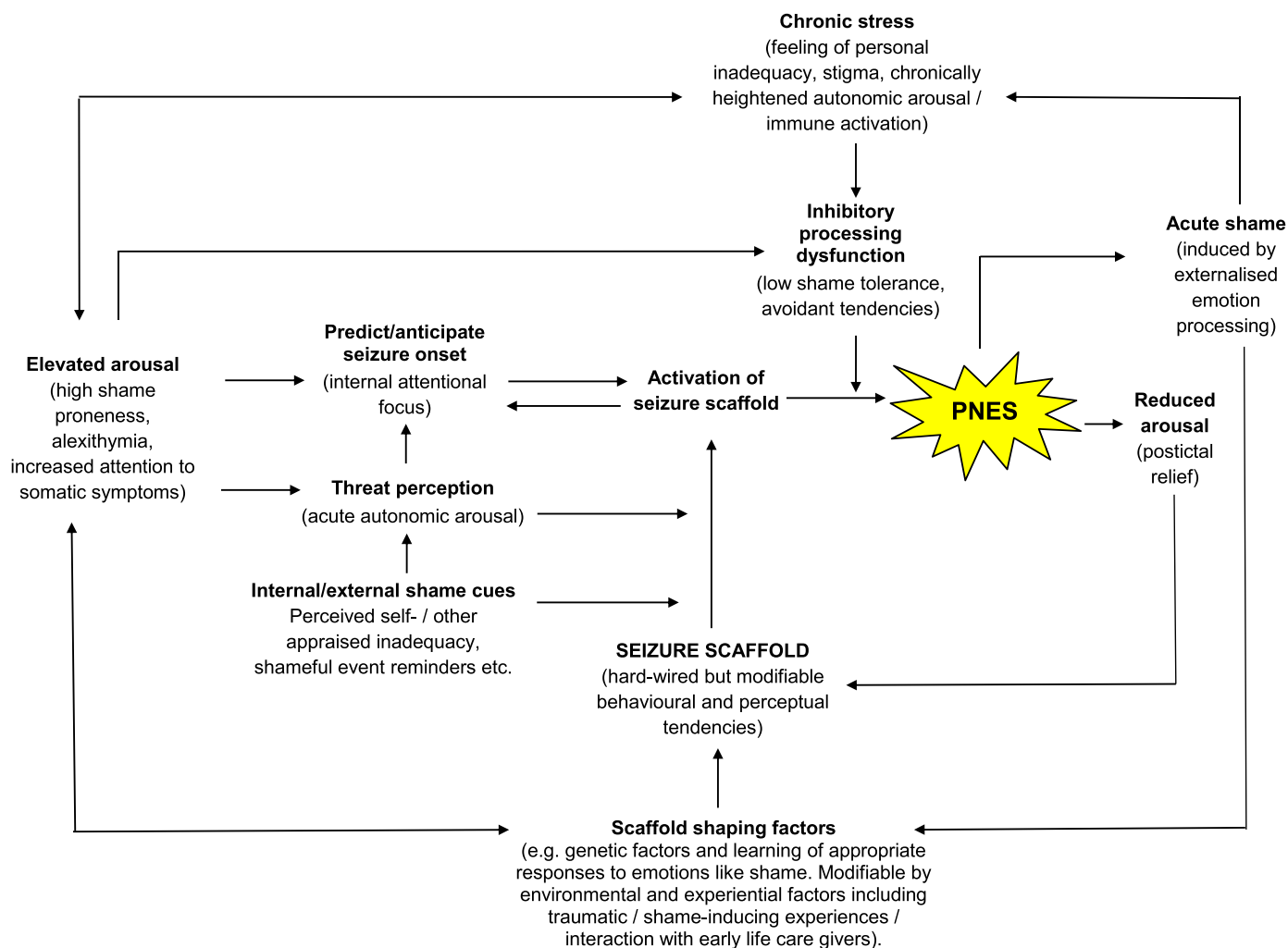


Fig. 1. Shame-associated processes feature in all key parts of the Integrative Cognitive Model (ICM). Genetic, inherent and learned aspects of shame processing as well as the dissociative and immediate physical reactions to shame (such as behavioural manifestations of rage) shape the seizure scaffold which can be triggered by external or internal shame-inducing stimuli. Chronic shame weakens inhibitory processes. Each PNES makes the next seizure more likely by providing acute “relief” from a state of acute distress and also by increasing chronic shame levels through the exhibition of a very private state of distress and unacceptable emotions associated with it - including self- or other-directed aggression (figure adapted from [23]).

Case 6: Seizures’ protective function against intolerable and shameful recollections.

A young woman developed PNES in her 20’s. She was an incest survivor who had been prohibited from making any disclosures to those outside of the family since a young age. Her PNES accompanied by severe depressive and PTSD symptoms emerged when she entered into a healthy and safe relationship. Her seizures protected her and her partner from these horrific recollections when something reminded her (e.g., intimacy, communication with her family of origin) but did not allow her to safely distance herself from her family of origin, gain help from others, to reinterpret her history, or to learn to tolerate her intense emotions. After she was able to trust her therapist and recount some of her most haunting and shame-ridden memories, she perceived herself and her parents differently, she was able to connect with her partner on a deeper level and her seizures ceased, as did many of her other symptoms.

develops through interaction with others, in relation to real or perceived caregiver or societal and cultural norms, and so shame can also be reduced in relationships with others. The therapeutic relationship provides a safe environment to explore the development of shame. This relationship needs a strong therapeutic alliance, firm boundaries, and empathic attunement. These qualities are likely to be more important than the treatment modality. At times, the therapist may need to halt a patient who is sharing too much, too soon (not least to prevent the kind of disengagement from therapy often encountered with the ‘emetic

patient’). This setting of boundaries around the pacing of disclosure ensures that the patient feels safe and contained enough to remember without being overwhelmed.

Compared to patients with PTSD (without PNES), the disclosure of shameful traumatic events by patients with PNES is complicated by the risk that such revelations might trigger seizures and disrupt treatment [26]. This may mean that any work on traumatic memories in this patient group will have to be preceded by psychoeducational interventions and exercises to raise patient’s awareness and tolerance of arousal.

Keeping a record of seizures and identifying triggers including intense emotions and interpersonal stress is very useful. Patients may also benefit from practicing sensory grounding techniques (e.g., holding an icepack or an object with various textures) allowing them to ‘stay in the room’ when dissociation threatens.

Mindfulness-based treatment (MBT, e.g., Acceptance and Commitment Therapy) that foster distress tolerance, emotion regulation, and self-compassion may be especially helpful in reducing guilt and shame. MBT presumes that by creating increased awareness and acceptance of internal states (including shame), patients can purposefully engage in values-based behaviour while automatized processes that lead to PNES decrease. Likewise, compassion-focused therapy (CFT; [27]), a psychotherapeutic system developed to address underlying emotional regulation, shame and self-criticism, might also be beneficial to this population.

Taylor recommends that, when trying to address excessive shame, the clinician focus on three potential domains: intrapersonal shame which can be evident through changes in self-concept; interpersonal shame at the intimate level, which can result in changes within the interpersonal realm; and interpersonal shame at a societal level, which could be represented through social loss, isolation, and segregation from health workers, family, friends, staff at work or school. In addition, it is recommended that the therapist be alert to signs of “unacknowledged shame” which may be represented by maladaptive shame regulation strategies such as acting out behaviours or substance abuse or the unconscious process of dissociation and seizures [19].

Furthermore, an integrative form of psychotherapy that combines gestalt psychology, emotion theory and concepts from mindfulness, emotion-focused therapy (EFT), can be useful in treating shame. According to Greenberg and Iwakabe [28], the “first principle of EFT designed to counteract shame is the development of a supportive, validating, empathetic, and affectively attuned relationship.” Once this relationship with the therapist has been established, the patient is encouraged to retrieve the shameful and humiliating experiences, acknowledging rather than avoiding them. Explicit shame regulation (e.g., sensory regulation through deep breathing or cognitive regulation through distraction and positive self-talk) as well as psychodramatic enactments (e.g., two-chair dialogue) or evocative imagery are employed in EFT. Shameful and humiliating outgrowths are substituted with internal strengths (e.g., self-compassion in place of blame, self-respect in place of self-disgust, primary adaptive empowering anger in place of internalized anger, and pride in place of shame).

Brief augmented psychodynamic interpersonal therapy for PNES that relies on the accepting and collaborative nature of the therapeutic work can encourage sharing of intimately shameful disclosures. Targets of this treatment modality include a) unhealthy patterns of interpersonal relationships, emotional processing, and working through of psychological trauma, all of which can be associated to shameful content [29]. Another brief variant of psychodynamic therapy (Intensive Short-Term Dynamic Therapy, ISTDP) tackles emotion recognition and tolerance very directly, ultimately aiming to enable patients cognitively to process guilt- or shame-inducing traumatic memories which would have triggered dissociation without the initial improvement of the patients’ emotion processing capacity [30].

Lastly, most trauma-focused treatment modalities [31–33] strive to examine and revise negative cognitions and distorted views of the self and others (e.g., shame and guilt, and the perpetrator role reversal) that often emerge during trauma disclosures and which then are examined and modified through processing interventions [31].

With regards to case 5, empathy, compassion and curiosity from the psychotherapist about how her early experiences were playing out in her relationship with the therapist, and in other situations allowed the patient to recognize the role shame had played and continued to play in her day-to-day life. In working on intrapersonal and interpersonal shame, the patient’s relationships with her husband and wider friendship group improved, and she developed greater self-compassion. The reduced

toxicity of the shame made it possible for her to ‘stay in the room’ with her husband, discuss issues together and to have fewer seizures. This patient perceived her role to be that of a dutiful daughter who thought of her sister and parents and did not need anything herself. The stirring of unacceptable emotions could leave her feeling shame to the extent that it could trigger a seizure, most likely in place of the intensity of her feelings of sadness or rage. For example, she had a seizure while watching television. Initially she had no idea what had triggered it. On reflection, she remembered an advert for young carers’ support. She consciously felt glad that other people would not go through what she had. With discussion she realized that she also felt huge sadness and perhaps anger that such services had not been available for her.

5. Shame and ending therapy

Psychotherapy can successfully end when patients’ retrospective analysis and meaning making of their distressing recollections have shifted from internalized, global, and unchangeable causal attributions to ones that are more fluid, externalized and event specific. In this way, the examination of the traumatic memories or other evocative thoughts ceases to evoke discomfort (e.g., shame, guilt, disgust, anger) so intense to cause emotional dysregulation, triggering PNES. These changes in cognitive and affective valence also allow the patient to remain grounded and emotionally regulated during future distressing experiences.

Given the nature of shame as a ‘social emotion’, normalization of shame processing is likely to require an interpersonal relationship such as the one provided in a psychotherapeutic setting. The successful resolution of shameful experiences is expected to result in improvements in self-concept, interpersonal relationships and reduction of anger, rage, depression, and other post traumatic symptomatology. By the time the therapy relationship comes to an end, patients will ideally have learned to identify and develop more constructive relationships outside therapy, providing safe contexts for experiencing any shame moments that subsequently occur.

6. Relationship between shame and outcome

To date, the effects of shame on outcome in patients with PNES have not been studied. However, experience from other psychopathologies suggests that, if shame is profound and remains untouched, and if the dysregulation of shame (especially shame tolerance) is not addressed in psychotherapy, symptoms may persist or re-appear after treatment termination.

In patients with PTSD, psychotherapy-associated improvements in feelings of guilt and shame have been reported amongst patients treated with empirically validated trauma focused treatments [33,34], although patients with higher pre-treatment levels of shame exhibit more PTSD symptoms at post-treatment and follow-up [35]. The fact, that core beliefs of guilt and self-blame were amongst the most common residual (post treatment) PTSD symptoms after therapy highlight the importance of addressing shame in treatment to reduce the risk of relapse. These findings in PTSD-alone may be relevant in our understanding of many patients diagnosed with PNES.

8.0 Summary

Effective treatments for PNES typically include comprehensive psychoeducation about the disorder, enhanced understanding of seizure triggers, and solidified awareness and tolerance of highly uncomfortable emotions such as shame, disappointment, rage, and resentment. The therapeutic process begins with the creation and communication of a credible and acceptable diagnostic formulation and ideally proceeds through relaxation and acute seizure management techniques (such as grounding techniques) to the application of methods enabling changes in perceptions, thoughts and actions. Specific modalities are less important than the eventual enhancement of emotional literacy and tolerance. In effect, shame (rage and other unmanageable emotions) is detoxified as a result of having a relational experience with the therapist

which is very different from that with their primary caregiver or from an imagined punitive society. Shame is created in relationships and needs a safe, non-judgmental relationship allowing patients to look back on their earlier beliefs and to recognize that beliefs that formed because of original traumatic events and emotional neglect (such as ‘I am a bad person, unlovable’ etc.) can be re-evaluated in the light of having a new experience in therapy.

7. Limitations

We fully acknowledge the limitations of this review and of our understanding of the relationship between shame and PNES, especially our extensive reliance on clinical experience. As noted in our companion narrative review paper [1], the subjectivity, lack of universally accepted definitions (of shame or PNES) or widely used validated measures make emotions such as shame difficult to study or discuss. These difficulties are compounded by the dearth of research specifically looking at the role of shame in those with PNES. In view of the lack of directly informative studies most of our arguments rely on anecdotal observations, associations or indirect evidence linking PNES with shame. Pending further research, we admit that, even if associations between PNES and shame exist, relationships may not be directly causal but implicate other factors including other emotions (such as rage, or even positive and complex mixed emotional states), but also comorbidities of PNES or shared risk factors for chronic shame or abnormal shame responses and PNES such as early childhood trauma.

8. Conclusions

Despite these limitations we think that there is a compelling case for clinicians to be alert to the possible role of chronic shame, shame sensitivity and shame tolerance in a fair number of patients diagnosed with PNES. While confirmatory research is needed, the well-recognised links between excessive shame and common comorbidities of PNES such as depression and PTSD and the many ways in which shame-associated processes can affect patients’ acceptance of their diagnosis, engagement in treatment, and treatment responses suggest that clinicians providing care for patients with PNES should be mindful of the presence and potential importance of this emotion in patients with this disorder.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the

Conflict of Interest statement

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