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Qualitative analysis of written accounts of functional / dissociative seizures

Abstract

Objective:
Subjective experiences of functional / dissociative seizures (FDS) are important for diagnosis and treatment formulation. This study aims to improve the symptomatological understanding of these seizures by analysing written narratives provided by authors with personal FDS experience.

Methods:
Descriptions of FDS were extracted from contributions to the book "In Our Words: Personal Accounts of Living with Non-Epileptic Seizures". Immediately preictal, ictal or postictal seizure symptoms were identified and subjected to summative content analysis. Themes and subthemes were derived inductively and deductively.

Results:
Of 93 authors with FDS who submitted contributions to the book, 75 mentioned seizure symptoms. In most narratives, FDS involved a complex, multidimensional symptomatology. Six superordinate symptom domains emerged: 'consciousness', 'movements', 'sensations', 'arousal', 'emotions', and 'cognition'. Within the superordinate theme of 'consciousness' (63/75 writings), 'awareness' was most frequently topicalised, followed by impairment of 'self-control/ responsiveness' and 'disconnection'. The second most prominent superordinate theme of motor symptoms (58/75 authors) included 'positive' (excessive activity), 'negative' (reduced motor activity) and 'mixed' symptoms. Accounts of sensations similarly included 'hypersensitivity', 'hyposensitivity' and 'mixed' symptoms. 'Pain' was another prominent sensory subtheme (13/75 narratives). The 'arousal' theme (20/75 accounts) captured 'hyper-' more often than 'hypoarousal'. In the superordinate theme 'emotions' (22/75 authors) 'anxiety' symptoms were particularly prominent. The superordinate 'cognition' theme (14/45 writings) mainly captured 'foggy thinking' and 'memory deficits'.

Conclusions:
In the words of individuals with personal experience, FDS emerge as complex and heterogeneous phenomena spanning physical, emotional, autonomic and cognitive domains. The characterization of FDS symptomatology should help with earlier diagnoses.

Qualitative analysis of written accounts of functional / dissociative seizures

Introduction

Functional / dissociative seizures (FDS), previously known as psychogenic non-epileptic seizures (PNES), are classified as a subtype of functional or dissociative neurological symptom disorder (most commonly abbreviated as FND) [1, 2]. FDS can involve visible manifestations which superficially resemble those of epileptic seizures or syncope. Therefore, it is not surprising that mis- and delayed diagnoses are common [3]. An accurate early diagnosis is a crucial first step in treating FDS, as it allows for the selection of the most appropriate treatment, namely psychological therapy [4], and the avoidance of unhelpful and potentially harmful interventions, such as the prolonged and unnecessary treatment of FDS with anti-seizure medications (ASMs) [5] or needless costly further investigations [6].

A number of reliable visible signs have been described to help clinicians make an earlier diagnosis of FDS based on "positive" features – as opposed to reaching a diagnostic conclusion through a lengthy process of eliminating all other possible causes [7]. However, the diagnostic reliability of these signs was determined in studies using video-EEG (VEEG) data, and they are unlikely to be as reliable if this diagnostic tool is not available. While the direct observation of seizure manifestations by experts or via home video recordings can be diagnostically useful [8, 9], other features which could help to distinguish between epileptic seizures and FDS in principle (such as altered respiratory patterns [10] and heart rate variability changes [11]) also require close ictal observation and recording. In circumstances in which video/VEEG recordings or direct observations are not obtainable or where there are few ictal motor manifestations, the differentiation is more difficult.

Despite the potential that they could contribute to an improved recognition of FDS and their differentiation from epileptic seizures [12], subjective seizure symptoms and experiences have, to date, received much less attention than visible seizure manifestations [13]. A deeper understanding of the subjective symptomatology of FDS is likely to be essential if the traditional approach of diagnosing FDS by the exclusion of epilepsy is to be replaced with the identification of "positive" diagnostic features of FDS [14]. Insights into the subjective experience of FDS will be required if features considered diagnostic of FND in general (like inconsistencies between observations and subjective experience reports) are to be described in relation to its seizure subtype.

The subjective experience of FDS symptoms may also have implications for treatment. For example, the presence of (at least partial) ictal awareness may provide a basis for communication with patients and for self-control or self-regulation interventions. A better recognition of initial seizure symptoms may allow patients to apply grounding techniques to stop an FDS from reaching the point at which it cannot be controlled [15]. Patient-reported FDS severity may be an important treatment target (and outcome measure) for many patients.

Most research investigating lived accounts of FDS to date has used quantitative methodologies. However, these approaches may oversimply people's experiences and restrict their ability to communicate what is most relevant to them. For example, by forcing individuals to pick their answer from a predefined categorical list of choices. In contrast, by allowing individuals to describe experiences in their own words, qualitative methods can provide richer and more nuanced insights. While most qualitative research has utilised semi-structured interviews to gather data [16], asking participants to write about their experiences may provide additional information given the private and more reflective nature of writing [17].

Aiming to contribute to a phenomenological understanding of FDS which could underpin a future definition of and diagnostic criteria for FDS, this qualitative study

examines written accounts of subjective seizure phenomena provided by individuals with personal experience of FDS [18].

Methods

Recruitment

In 2015, the editorial team of the book entitled, *"In Our Words: Personal Accounts of Living with Non-Epileptic Seizures (The Brainstorms Series)"* (MR, GHR and SCS) invited individuals with personal experiences of FDS as patients or caregivers to contribute their written account of living with the condition. Potential authors were recruited via the websites of organizations supporting people with FND, including FND Hope and FND Action. Contributors were also recruited via clinicians working in the field and among the participants with FDS of a previous research study examining the effects of a therapeutic writing intervention [19]. While the editors aimed to recruit authors from around the world, submissions had to be made in English.

The solicitation of writings continued through 2016 until the target of at least 100 contributions had been met. All submissions were included (even if they replicated accounts already provided by others). All authors provided written consent for the inclusion of their account in the book during the online submission process. Submissions were lightly edited. Authors were asked to give their final approval for publication of their work after grammatical errors and typos had been corrected, and personal identifiers altered.

Data collection

Authors were not given any guidance on the style or maximum length of contributions in the invitation letter. However, they were told that the book was inspired by a book entitled "Epilepsy In Our Words: Personal Accounts of Living with Epilepsy" and the Brainstorms series of books which followed on from this original

publication [20]. To make it easier for individuals to write about challenging experiences and to protect their identity, authors were told that their submissions would be anonymized. Authors were given the opportunity for their names to be listed in the published book although their names would not be associated with specific contributions.

In the invitation letter, potential authors were encouraged to consider the following questions in their writings:

"What it is like to live with non-epileptic seizures, or what you experience before, during and after your non-epileptic seizures? How do your non-epileptic seizures affect your day-to-day life?" They were reassured that *"we are interested in your story told in your own words, and you can write about anything you feel is important."* They were told that they could also write about *"how the non-epileptic seizures have affected your relationships with others such as family members, friends, neighbors and work colleagues, or how your family, friends, doctors, nurses, therapists, paramedics and even complete strangers have reacted to your seizures. Have the seizures had an impact on your independence and financial stability, your work life and career? How have the seizures affected the way you feel about yourself and about how others see you?".*

Data analysis

In an initial analytic step, the authors (QX, MR and GHR) closely read all contributions to the book and identified sections of text containing descriptions of FDS. The descriptions and their immediate context were extracted from the text and submitted to summative content analysis with the aim of identifying common themes and subthemes [21]. Specific symptoms could be associated with several themes or subthemes if appropriate. During our analysis we independently considered the allocation of symptoms to themes and discussed associations until we had achieved consensus. While most themes emerged inductively from the data, we added an element of deduction to name some aspects of FDS semiology, which were clearly evident from the data to communicate the multidimensional phenomenology of these

seizures (such as symptoms reflecting activations of the autonomic nervous system likely to reflect hyper- or hypo-arousal).

We introduced subthemes to structure certain symptom-types. For instance, we deductively differentiated between "positive" and "negative" motor or sensory symptoms. Our choice of these categories was inspired by well-established previous distinctions between FDS with increased motor activity (i.e. convulsive FDS) and seizures with reduced motor activity (such as "swoons") [22]. Like the neurological distinction between "positive" and "negative" sensory symptoms (characterized by hypersensitivity / sensory hallucinations versus hyposensitivity / anesthesia) the distinction between "positive" and "negative" motor symptoms also has some pathophysiological significance: "positive" motor phenomena tend to be related to activation / overactivity whereas "negative" symptoms are typically related to inactivity / suppression of neuronal networks.

Our methodology involving convenience sampling of authors and a lack of prompts guiding authors to provide a comprehensive report of their seizure symptoms did not allow us to report the prevalence of symptoms. However, we interpreted the frequency with which authors chose to report particular aspects of their seizure experiences as a reflection of the relative prominence of specific symptoms. We therefore have reported the different aspects of FDS symptomatology emerging from the available accounts in the order of the frequency with which they were reported.

Written accounts were first collected for the purpose of the book (*"In Our Words: Personal Accounts of Living with Non-Epileptic Seizures (The Brainstorms Series)"*. At the time of submitting their accounts for the book, authors were not made aware of the possibility of using the data for research in the future as it was never the aim until now. For the current study, we obtained assurance from the Ethics Committee at the University of Sheffield that the use of previously published accounts for the purpose of our intended analyses would not require additional consent from authors or formal ethics approval. No new data or data that had not been previously published in the book were analyzed for the purpose of this study. All data analyzed in the current

study can be accessed via the aforementioned book.

Results

Authors

Of the 105 contributions to the book documenting firsthand experiences of living with FDS, 93 were from individuals who had experienced seizures themselves. The 12 contributions from caregivers or relatives were not used for the present analysis as we focused on self-reported symptoms. With the exception of a single contribution from Kenya, all writings were submitted by authors from high income Western countries (predominantly the UK and the USA). Descriptions of immediately pre-ictal, ictal and postictal manifestations of FDS were identified in 75 (80.6%) of the 93 personal accounts. These 75 accounts containing FDS descriptions were used in the analysis.

Experiences

In 12 (16%) of the 75 accounts, authors provided a global description (e.g. C24 *"scary feeling"*; or C90 *"violent convulsion"*) or minimal detail about their seizure experiences (e.g. C22 *"I know that my triggers are related to noise and crowds, and feeling trapped."*; or C103 *"I had slipped on some ice in my mother's driveway and do not know how long I was unconscious."*).

The other 63 writings (84%) included more extensive, multidimensional accounts. This means that, when more detailed seizure descriptions were provided, they were of a multifaceted experience involving symptoms which could be grouped into six superordinate themes. We identified symptoms related to: "consciousness", "movements", "sensations", "arousal", "emotions" and "cognition". All superordinate themes had subthemes. Two sub-themes were not related to one but two superordinate themes: "communication" contained elements of the higher order themes "consciousness" and "movements", while the subtheme "disconnection" was related

to the themes “consciousness” and “cognition” (see table one for the frequency with which different themes were included and figure 1 for a graphic representation of the themes).

Table 1 and figure 1 near here

1. Consciousness

Within the superordinate theme of consciousness (which featured in 63/75 writings), the subtheme “awareness” was most prominent (42/75 accounts). Descriptions of the impairment of self-control or responsiveness were the second most prominent subtheme (discussed by 25/75 and 12/75 authors, respectively). The final subtheme “disconnection” (15/75 authors) involved aspects of both “consciousness” and “cognition”.

1.1 Awareness

While 19/75 authors described a loss of awareness (contributor (C)40 *“I am absent and start falling down and then have convulsions. During that time, I am completely unconscious. I do not respond to pain stimuli”*), and 12/75 mentioned partial loss of awareness (C14 *“dazed, but probably with no loss of consciousness”*, C15 *“I can recall odd parts”*), 11/75 described that they remained fully aware during their seizures (C23 *“I have never lost consciousness. I am always able to hear what is going on, and though my eyes cross, I can see and keep track of who is around me.”*). There was also a suggestion that authors could have a degree of awareness during their seizures, but no recollection of this afterwards (C19 *“I repeatedly lost consciousness and even began to lash out in anger, and what I can only imagine now was some kind of visual hallucination.”*).

1.2 Impairment of self-control / responsiveness

Lack of responsiveness could be associated with complete loss of awareness (C40 *“During that time, I am completely unconscious. I do not respond to pain stimuli.”*),

but absent or reduced self-control or responsiveness could be experienced as particularly distressing when it occurred while authors were fully aware of themselves and their surroundings (C101 *"I will cry in anger during my attacks as I am aware of what is happening; I am just failing to control it and unable to respond."*).

One specific manifestation of impairment of self-control / responsiveness that was given prominence by authors was the inability to communicate (mentioned in 23/75 accounts). In the analysis of communication problems, it was not always possible to distinguish between difficulties associated with impaired consciousness, or the inability to generate speech due (C41 *"You can hear the voices of the people around you. But your brain has suddenly forgotten how to respond."*) such as because of problems with motor control, i.e. being unable to produce speech when knowing what to say (C73 *"I am aware what's going on, I just can't make a sound."*). Communication could also be impacted by difficulties with understanding speech (C31 *"When I feel myself going mushy, as I call it, I can't make out conversations; they like all jumble together."*).

1.3 Disconnection

Some authors reported feeling *"disconnected"* without loss of awareness (C23 *"I have never lost consciousness. I know that I'm in my body, but I'm not connected to it."*). However, others experienced disconnection in combination with alterations in consciousness (C92 *"I wake up to find myself somewhere strange… Her voice is really distant. So distant that it is inaudible."*). Some complaints of disconnection were accompanied by cognitive impairment (C5 *"I cannot hold thoughts. I feel as if I'm separated from my body. I can still hear everything and I am aware of what is happening. I feel very disconnected to my body."*). A particularly striking aspect within the subtheme *"disconnection"* was the loss of identity or self-recognition, described by three participants (C19 *"I lost all awareness of who I was."*).

2. Movements

Motor symptoms were the second most prominent supraordinate theme. At least

one motor manifestation was recorded by 58/75 authors. “Positive” symptoms included shaking movements, tremors, twitching motions, convulsions or body rigidity (41/75 accounts). Meanwhile, symptoms classified here as "negative" included drop attacks, episodes of collapsing, and paralysis (38/75 accounts). Motor symptoms could also be “mixed”, for example contain “positive” and “negative” elements (21/75), such as falling down and having a convulsion (implying a limp collapse followed by “positive” motor manifestations).

2.1 Positive motor features

Some authors who reported *positive* symptoms described themselves as fully or partially aware (15/75; C44: *“I was completely conscious… My body began thrashing wildly, my head was jerking from left to right, and my limbs were hitting my body and the bed.”*). In keeping with this, authors mentioning positive motor features often mentioned an associated feeling of loss of control (C92: *“I’m losing control of my body, I become tense, so tense I’m shivering.”*).

“Positive” motor manifestations included “positive” vocal manifestations such as screaming (3/75; C65: *“I was jerking and screaming...I would jerk and make funny noises.”*)

2.2 Negative motor manifestations

Authors who only reported negative motor symptoms were more likely to mention associated impairment of consciousness (17/75; C86: *“I could barely walk... The next thing I remember, I was in the ambulance.”*). However, negative motor features were also reported by authors who described themselves as being aware at the time (6/75; C65: *“I could not move any part of my body during the blackout, but I was conscious and could hear all that was said.”*).

Additionally, “negative” vocal manifestations, such as not getting words out were also included (C73: *“I am aware what’s going on, I just can’t make a sound.”*).

2.3 Mixed motor symptoms

More than one third of the authors who mentioned movement complaints described mixed positive and negative motor symptoms (C73: *"I can't walk, which leaves me paralyzed. My head slowly begins to nod up and down, my right arm begins to tremor and shake."*).

3. Sensations

Many accounts contained descriptions of a range of sensory symptoms (41/75 accounts). Some authors reported increased sensitivity. Pain in different parts of the body was a particularly prominent sensory symptom. However, other authors described experiencing reduced sensitivity or a mix of hyper- and hyposensitivity in a single episode or in different attacks.

3.1 Increased sensitivity

Reports of increased sensory sensitivity or hallucinations referred to different modalities: Tingling was described most frequently (5/75; C51: *"a strange tingling and burning sensation all over my body"*). Other sensory symptoms included taste (2/75; C49*: "a metallic taste"*) and smell (2/75; C66: *"I can smell odd smells."*). Two people highlighted how their hearing was "acute" during their seizures (C94: *"My hearing is acute, and so I hear all the laughter."*)

3.2 Pain

Pain featured in 13/75 accounts and could affect various areas of the body. Head pain was mentioned by eight people (C46: *"It starts with a sharp, shooting pain in my forehead"*); back pain by one (C5: *"pain in my side and upper back."*); abdominal pain by two (C11: *"severe abdominal pain"*), and pain in the limbs and body by five (C86: *"My whole body hurt."*). Three authors reported multifaceted pain in at least two parts of their bodies (C25: *"my arms and legs become achy… I felt my head was burning. The pain is like being electrocuted from the brain down through my spine."*).

3.3 Reduced sensitivity

Hyposensitivity was most frequently (in 6/75 writings) reported as "numbness" (C65: *"I felt numb."*), or blurred vision (C64: *"my vision got very blurry"*). One author mentioned reduced hearing (C92: *"Her voice is really distant. So distant that it is inaudible."*), while another described complete absence of sensation (C66: "I had no feeling or sensation in the lower part of my body.").

3.4 Mixed sensations

Lists of more than one sensory symptom were provided by 19/75 authors (C10: *"worms-crawling-in-my-legs feeling… My head was screaming in pain. My right leg burns. My right arm burns as well, and then becomes very cold."*)

4. Arousal

Some authors (20/75) noted symptoms of sympathetic nervous system activation, especially heightened arousal (C5: *"a fight-or-flight sensation"*) and perception of cardiac activity (5/75) suggestive of autonomic arousal (C73: *"my heart rate pounds"*). In contrast, 10/75 patients described symptoms reflecting hypoarousal or fatigue (10/75; C1 *"I stare into space, mumbling, and with heavy eyes"*).

Seven authors mentioned changes in breathing patterns, with tachypnoea (suggesting hyperventilation, 5/75) being the commonest respiratory FDS manifestation (C92: *"My breaths are getting faster."*). One person reported hypoventilation (C61: *"feeling weakness in my limbs and breathing slowing down"*) or gaps in respiration (C104: *"I passed out and stopped breathing for a short while."*).

Loss of bladder control was reported by 6/75 authors, (C52: *"Sometimes I lose bladder control"*.)

5: Emotions

Emotional seizure manifestations were mentioned by 22/75 authors. Whereas 15 authors referred to a single emotion, seven described more complex emotional states.

Panic, fear or anxiety were most prominent. “Panic” was mentioned by seven authors: Four felt panic during a seizure (C15: *“I remember all of a sudden feeling panicked, sweaty, and dizzy, and saying I couldn’t move.”*), the other three just before a seizure (C41: *“I will feel dizzy, my blood pressure drops, I will feel panic, I will feel anxious and scared and experience the warning sign, which is that feeling of dissociation from everything. And then that’s when the seizures happen.”*).

Feeling “scared” or experiencing the situation as “scary” was the second most common description (6/75). Four people reported “dread” or “fear” (C85: *“familiar feeling of dread and fear rising from deep inside my abdomen like a porcupine coming from the inside, then spreading outward.”*). Four people described feeling “tense” or “anxious” (C100: “I was feeling anxious.”); three authors felt they could be dying (C20: *“I believed that I was indeed dying.”*)

Other emotions (in 4/75 accounts) included anger or irritability (C19: *“I repeatedly lost consciousness and even began to lash out in anger.”*).

6: Cognition

Fourteen people described experiencing cognitive problems: Six reported memory loss (C83 *“lost my short-term memory.”*), while three used the term “foggy” to describe their subjective experience of how their brain was functioning (C4 *“I become foggy, and thinking/memory becomes difficult.”*).

Discussion

Our analysis of written accounts from 75 adults with personal experience of FDS indicates that the subjective manifestations of these seizures are highly heterogeneous. There are marked interpersonal differences in FDS symptomology: whereas one person may experience complete loss of awareness of the actions they carry out during a seizure, another may experience retained awareness in the context of an inability to act. FDS may involve positive, negative or mixed motor and sensory

features, as well as autonomic hyper- or hypoarousal. The variability of these observations matches the findings of a previous ictal symptom-questionnaire study in which (n=100) patients with FDS reported much more heterogeneous experiences of transient loss of consciousness than those who had clinically proven diagnoses of syncope (n=100) or epilepsy (n=100) [12].

Resonant of previous studies of the interactional behaviour of patients with FDS, which identified an apparent reluctance to describe their seizure symptoms in detail [23, 24], about one in five of authors chose to respond to the invitation to write about their personal experiences of living with FDS without providing any seizure descriptions, and another twelve produced minimal descriptions. However, most contributors provided multifaceted accounts of complex experiences often involving somatic symptoms as well as emotions, cognitions, and behaviors.

Different types of alterations of consciousness, including impaired awareness, unresponsiveness, and loss of control were the most prominent theme in our data. Like in a previous study of FDS semiology applying content analysis to interview transcripts [25], descriptions of loss of consciousness were similarly frequent as those of partially or completely retained consciousness without an ability to react. These findings also match those of an earlier questionnaire-based study which demonstrated higher levels of ictal consciousness and greater content of consciousness in patients with FDS than among patients with epilepsy [26]. Likewise, when compared to patients with syncope or epilepsy, those with FDS, were able to report more ictal symptoms in the study with 100 participants in each group mentioned above than those in the other two groups [12]. These self-report-based studies concord with a study based on the direct ictal and postictal examination of patients with FDS or focal impaired awareness seizures which have demonstrated that more patients with FDS are partially responsive in their seizures and able to recall aspects of what happened during their seizures when questioned after the event [25, 27].

Lack of responsiveness or self-control with retention of awareness emerged as an

experience of FDS, which may be particularly characteristic of these seizures. This ictal state corresponds to that of 77/100 (77%) participants with FDS who endorsed the statement “In my attacks I am conscious but I can’t react to things” in the questionnaire-based study mentioned above [12]. The differential characteristics of patients with FDS reporting either loss or preservation of ictal responsiveness were previously compared in a study by Baslet et al [28]. In their study, 47/71 patients (66%) reported ictal loss of responsiveness. Patients with loss of responsiveness had lower levels of emotional resilience and higher levels of avoidance; they did not differ from patients without loss of responsiveness on measures of psychopathology, somatic symptoms, or trauma history.

A lack of self-control causing an inability to communicate was particularly highlighted by a substantial subgroup of authors in the dataset analyzed here. Communication could also be impaired by a transient incapacity to understand or follow speech or to formulate language. Previous studies have described ictal stuttering as a feature highly suggestive of a diagnosis of FDS rather than epilepsy [29]. Postictal whispering has also been identified as a behavior more likely to be observed after FDS than epileptic seizures [30]. The “unspeakable dilemmas” which are often found to be associated with FDS disorders could provide a psychodynamic explanation why authors highlighted difficulties with communication as a particular feature in their writings [31], but in the absence of studies investigating the relative prevalence of particular ictal symptoms in different subpopulations of patients with FDS, it currently remains uncertain why some authors have highlighted this particular problem.

When consciousness was at least partially preserved, many authors described symptoms suggesting that they felt disconnected from their surroundings or their own thoughts and feelings. Authors volunteered examples of all five aspects considered to be characteristic of dissociation: depersonalization, derealization, amnesia, identity alteration and identity confusion [32]. In more extreme cases they felt disconnected

from themselves, and lost access to their own identity. The prominence of symptoms suggestive of dissociation has caused experts to argue for several decades that FDS should be interpreted as a dissociative disorder [33, 34]; and dissociation (i.e. a process of disintegration of cognitive, emotional, and sensorimotor processes associated with the display of automatic motor behaviors without volitional control) continues to play a key role in current psychological models of FDS [35, 36]. In these models, processes associated with dissociation are central to switching from a state characterized by heightened arousal and potential distress to one that is more tolerable and typically associated with hypoarousal [37, 38]. While the findings of this study support the idea that dissociative symptoms are prominent in patients with FDS, the mode of data collection (with no option to seek clarification from authors) limits possible insights that self-report accounts might provide into the direction of the relationship between dissociation, impairments of consciousness and activation patterns of the autonomic nervous system.

The second most prominent superordinate theme was related to movements. As with alterations of consciousness, there was a diversity of different motor symptoms. Reported involuntary movements included tremors, jerks, shakes, convulsions, abnormal postures and collapses. The frequency of "positive" and "negative" motor phenomena seemed to reflect the findings of previous studies. For example, a study by Asadi-Pooya indicated that 55.6% of patients (35/63) had "generalized" motor seizures, 19% (12/63) had akinetic seizures, and 3.2% patients (2/63) presented with episodes resembling "focal motor" seizures [39]. The significance of predominantly "positive" or "negative" motor phenomena in the context of FDS remains uncertain, although previous studies suggest that prominent convulsive movements may be associated with higher levels of previous sexual abuse [40], distress and somatic symptoms as well as poorer outcome [41, 42]. In a large study aiming to identify subgroups within the population of FDS, "hyperkinetic" seizures were most commonly seen in the cluster characterized by high levels of lifetime (including sexual) trauma and female preponderance, whereas seizures with "non-hyperkinetic"

motor manifestations were typical of a cluster of patients who had experienced no (or a single) trauma and who were more likely to be male and have comorbid epilepsy and low educational achievements [43].

While ictal sensory symptoms could be "positive" (becoming aware of a stimulus that is objectively not present) or "negative" (noticing the absence of perception in the presence of a stimulus), the single most prominent sensory symptom was pain. It is well recognized that fibromyalgia, chronic pain and regular analgesia use are common among patients with FDS [44-46]. The prevalence and characteristics of seizure-related pains have, in contrast, not received much attention to date, although the presence of ictal pain should be particularly helpful in the differential diagnosis with epilepsy where pain is an exceptionally rare complaint [47].

The superordinate theme "arousal" was identified deductively although symptoms arguably associated with autonomic hyper- or hypoarousal were reported by a relatively large subgroup of authors. Symptoms likely attributable to hyperarousal were most common. These symptoms could be interpreted as physical/somatic manifestations of anxiety. The fact that they were discussed more prominently than emotions such as panic, fear or anxiety resonates with the findings of previous studies that demonstrated patients with FDS may be more sensitive to physical than the emotional / cognitive symptoms of anxiety [48]. This observation has given rise the idea that (at least some) FDS could represent attacks of "panic without panic" [49].

When authors mentioned ictal emotions, symptoms of panic, fear or anxiety were most prominent. Emotions could be highly distressing and include the fear of dying in a seizure. In highlighting the particular role of anxiety-related emotions as ictal symptoms, our findings replicate those of previous interview or questionnaire-based studies which demonstrated that panic symptoms were more common during FDS than epilepsy, and that they were of reasonable differential diagnostic value [50, 51].

Although our study could draw on a sizable dataset, it has several limitations. Given that participant enrollment was based on convenience sampling and involved individuals willing to write about their seizure experiences, we cannot be certain that our sample was representative of the whole FDS population. For instance, we need to acknowledge that almost all contributing authors were from high income, Western countries. Our findings may therefore only represent the seizure experiences of individuals with this cultural background. The fact that the participants self-declared their diagnosis and that the book includes contributions from authors whose diagnoses were never proven by video-EEG could be seen as another limitation. However, this also means that the group of contributors may have been more representative, as only patients with particularly frequent FDS are likely to be investigated with VEEG, while (at least in the UK) the majority of patients are diagnosed on clinical grounds or using home video recordings [52]. We acknowledge that the secondary use of data from a book intended to capture the whole experience of living with FDS is associated with problems which limit the interpretability of our data. We did not prompt authors to include complete accounts of all their seizure symptoms or provide individuals with a list of possible seizure symptoms as a reminder or prompt - although the use of such lists would likely have increased the number and diversity of reported symptoms [53]. While this weakens any conclusions based on the frequency with which particular symptoms were mentioned, the way in which we acquired the data means that the symptoms which authors shared were likely to have been particularly prominent and important to them. Last but not least, we acknowledge that our mode of data analysis did not extend to linguistic methods which have previously been used in studies contrasting the language used by patients with FDS with that used by those with epilepsy in clinical interactions with physicians. While written seizure descriptions could be subjected to the kind of analysis of metaphor use or label preferences which previously yielded interesting differential diagnostic observations [54-56], such analyses would require the additional examination of similarly collected data from patients with epilepsy. What is more, these linguistic features would not be readily observable by clinicians as they talk to their patients.

In conclusion, FDS emerges from people's writings as a heterogeneous experience involving a complex mix of physical/somatic, cognitive, motor, autonomic and emotional symptoms. While the variability of FDS manifestations may contribute to the diagnostic challenge these seizures pose, the pattern of subjectively reported seizure experiences is markedly different from epilepsy or other differential diagnoses of FDS. The recognition of typical FDS experiences, especially a prominent sense of reduced self-control, should therefore help clinicians to arrive at a diagnostic conclusion based on "positive" features rather than solely by excluding other disorders.

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