What are non-epileptic seizures, and why do people have them?

ABSTRACT

Psychogenic non-epileptic seizures (dissociative seizures) are encountered commonly in emergency medicine and in acute medical wards. Although diagnosis is usually deferred to an expert in epilepsy, an understanding of the phenomenon is helpful in acute management of the patient and dealing with associated urgent safeguarding issues. This article describes a simple model of psychogenic non-epileptic seizures that is useful in clinical practice and helpful to staff, patients and their carers.

CASE STUDY: PART 1

A woman in her early 20s attends the emergency department with her mother. They are distressed and the mother describes multiple daily blackouts affecting her daughter over the last few weeks, each lasting up to half an hour. The description is of variable types of episode, sometimes accompanied by shaking, sometimes just staring into space. The patient herself can give scant details of what is happening during the attacks.

Several previous visits to the emergency department have been unrewarding, although it has been suggested that the GP should refer her for a neurology opinion, and the mother complains that their problem is not being taken seriously. Discharge summaries mention possible 'pseudoseizures'. The family asks you to do something urgently to help. You know it will take several weeks to get an outpatient neurology review.

When an experienced clinician assesses a clinical problem there is always a judgment to be made as to how much of the symptomatology is physically, and how much is emotionally determined. There is increasing interest in the phenomenology of symptoms that are medically unexplained, especially among neurologists, who often frame them as 'functional neurological symptoms' (Carson et al, 2011). It has been estimated that patients with predominantly or exclusively psychogenic symptoms comprise one third of most doctors', including neurologists', workload (Stone et al, 2010), but despite their frequency, few clinicians feel comfortable in assessment and management of these conditions.

Psychogenic non-epileptic seizures (also known as non-epileptic attacks, pseudoseizures or dissociative attacks) (*Case study: part 1*) are in some ways the most straightforward type of functional symptom for a neurologist to diagnose (Reuber and Elger, 2003) unequivocally, based on video recordings of the events or electroencephalograpy capturing the attack. However, when faced with a patient in the emergency room or general medical clinic setting, there is uncertainty about the diagnosis. Understanding why these events happen gives general or emergency room physicians insights into how to provide immediate support and consider safeguarding issues that may be inferred. Understanding non-epileptic attacks can lead a clinician to a greater understanding of other medically unexplained symptoms, and perhaps ultimately to a more satisfactory doctor–patient relationships.

The diagnosis of transient loss of consciousness (National Institute for Health and Care Excellence, 2014) is often challenging, and differentiating between psychological and neurological symptoms is difficult even for the expert. This article does not intend to help non-specialists make a diagnosis, but instead provides a simple model that can be easily understood by both clinician and patient to help understand psychogenic non-epileptic seizures when they are encountered. Such models are necessarily incomplete and will likely be elaborated on and developed by interested clinicians, but should be sufficient for most clinicians assessing patients with blackouts. This article provides a framework for explaining the problem to the patient and initiating first-line management.

Incidence and prevalence

Psychogenic non-epileptic seizures, epilepsy and syncope together comprise over 90% of clinical presentations of transient loss of consciousness. The incidence and prevalence of psychogenic non-epileptic seizures is difficult to estimate. The diagnosis is certainly influenced by physician awareness and expertise, and also likely the availability of effective psychological treatment.

About 20–30% of patients referred to epilepsy clinics have psychogenic non-epileptic seizures as the principal problem, but the prevalence is higher in those with refractory seizures. Published estimates of the prevalence lie between 2 and 33 per 100 000 population (Benbadis and Hauser, 2000), making it a significant neurological problem with a prevalence similar to that of cystic fibrosis or tuberculosis. Women predominate over men, and the peak incidence is between the ages of 15 and 24 years. The condition is often diagnosed late (mean delay 7.2 years; Reuber et al, 2002), as the result of revision of a prior diagnosis of epilepsy. The condition almost certainly absorbs a disproportionate medical resource for

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its prevalence, as it is characterized by frequent calls on emergency services and distress affecting the whole family. Erroneous treatment of psychogenic non-epileptic seizures with antiepileptic medication exposes the patient to risk of adverse effects of antiepileptic drugs, including teratogenic risk, and increases the economic burden on the patient, carers and health services (Fritzsche et al, 2013; Magee et al, 2014).

Phenomenology

Psychogenic non-epileptic seizures are variable in clinical appearance (LaFrance et al, 2013; Reuber and Brown, 2017) and this likely contributes to difficulty and delay in diagnosis (*Case study: part 2*). Because people with psychogenic non-epileptic seizures have frequent and prolonged seizures that are resistant to medical treatment, clinicians witnessing seizures in primary and secondary care are more likely to witness a non-epileptic seizure than an epileptic one. Often the only clues to the diagnosis are verbal descriptions from witnesses, which are of limited value. Descriptions of attacks prolonged for more than 10 minutes, those that are recurrent within a few minutes, those who appear to have multiple different types of seizures at different times, and those where movements wax and wane and move from one part of the body to another, and where seizures stop and start should raise the possibility of psychogenic non-epileptic seizures, as should a history of other functional (i.e. emotionally-generated) symptoms in the patient. Side to side movements of the head, partial awareness or responsiveness during the seizure, lying motionless as if asleep for many minutes and crying afterwards are strong indicators of psychogenic non-epileptic seizures. Most witnesses, including medically trained personnel, cannot reliably provide such detail, and the attacks are commonly described as 'grand mal' or 'shaking' without further detail even by medical staff.

Subjective descriptions of psychogenic non-epileptic seizures are typically featureless and characterized by negative descriptors ('I don't know'). Patients often have difficulty estimating the frequency of the events, their duration and their physical accompaniments, and may concentrate mainly on their impact and emotional fallout.

Eyewitnesses may describe some preservation of consciousness, fluttering of eyelids and changes in the seizure in response to attempts at interaction with the sufferer. Eyes may be closed and eye opening resisted. Side to side movements of the head and sinusoidal shaking of the limbs (as opposed to myoclonic jerking, with a fast phase in one direction) are also reasonable predictors of psychogenic non-epileptic seizures, as is unusually sudden recovery (or in contrast prolonged motionless unresponsiveness). Witnesses may also describe variation in type or duration of attacks, in contrast to epileptic seizures that tend to be stereotyped. Very prolonged attacks (more than 10 minutes) are unlikely to be epileptic, and post-ictal crying is a strong pointer to the diagnosis. Unfortunately, no feature is entirely specific or sensitive.

Some of the indicators that are classically used to determine that a seizure is epileptic turn out to be unhelpful. Some degree of mouth trauma resulting in bleeding from the mouth is common in psychogenic non-epileptic seizures (although a substantial transverse tongue laceration is not), as is urinary incontinence and minor injury, including carpet burns, abrasions and lacerations. Neuroimaging is most often normal in both epilepsy and psychogenic non-epileptic seizures.

CASE STUDY: PART 2

The patient tells you that she gets little warning of the attacks but finds them very upsetting. She does not think she is conscious and cannot say how long they continue or how often they occur.

Her mother shows you a video of one on her mobile phone – it shows her daughter lying prone on the sofa with her army and legs shaking vigorously. There are writhing movements of the trunk and pelvis that wax and wane. Her eyes are closed and her head is moving from side to side. She is drooling and retching. She does not respond to her mother. This continues off and on throughout the 3-minute recording.

You notice multiple scars of self-harm on the patient's arms, and the case notes record that 3 years ago she was seen in the emergency department after an impulsive overdose of paracetamol.

Diagnosis

A specialist in the subject of epilepsy and non-epileptic seizures should usually make the diagnosis of psychogenic non-epileptic seizures, usually (but not always) a consultant neurologist in the UK and with access to facilities for video electroencephalography telemetry (Reuber, 2019). Unfortunately, laboratory, neuroimaging and standard 'inter-ictal' electroencephalography are often unhelpful. The gold standard of video electroencephalography telemetry is invaluable in confirming the diagnosis if it records an event, but does not necessarily exclude the possibility of co-existent epilepsy in those with psychogenic non-epileptic seizures. It is an expensive and scarce resource in the UK.

Recordings of seizures on mobile telephones are an invaluable tool to facilitate diagnosis and should be encouraged, although sometimes this suggestion is met with hostility and should be introduced into the consultation sensitively. Patients are often extremely embarrassed about their attacks, and partners, carers or family may resent the idea that the recordings are made when the patients are in a public place and at their most vulnerable. Such recordings may demonstrate patients lying motionless 'as if asleep' for prolonged periods, sinusoidal fluctuating and evolving rhythmical limb and body movements which change in position, amplitude and frequency during the attack, side to side head movements, arching of the back, pelvic thrusting, and crying during or afterwards. Patients may resist handling or strike out during the seizure, and recovery may be sudden (or alternatively unusually prolonged).

Association with trauma

Those with psychogenic non-epileptic seizures are significantly more likely to have experienced physical, emotional, sexual and other trauma than those with epilepsy (Myers et al, 2013), and this is plausibly of aetiological significance in the commonest type of psychogenic non-epileptic seizures (dissociative attacks) (*Case study: part 3*). It is often useful to explain this to patients, using a simple definition of trauma (i.e. something or things which have happened to the patient which are outside his/her control and intolerable or unacceptable).

What is happening in a psychogenic non-epileptic seizure?

Psychogenic non-epileptic seizures are a form of disturbed consciousness, very distinct from 'coma' or 'sleep' with which clinicians feel familiar. This impairment of conscious experience during the attack has to be explained to the patient if he/she is to understand and accept the diagnosis fully.

The commonest type of psychogenic non-epileptic seizure is the dissociative attack. Dissociation as a psychiatric term often makes clinicians uncomfortable, as it means the separation of mental processes that are normally integrated. Clinicians may feel uncomfortable delving into psychiatric or psychological aspects of health, and may feel this issue is outside their scope of competence. However, in principle, dissociation is not difficult to understand or explain. It is a more or less willful direction of attention away from something that has become prominent in conscious thought. It is useful to consider this concept in greater detail.

Dissociation is an idea that has its origins in Janetian and Freudian theories (Ellenberger, 1970), and its nature and relationship with trauma has been contentious. To a medically-trained and psychologically inexperienced clinician, the concept may appear alien and implausible, as it depends on an idea of separation of conscious, voluntary and willfully directed thoughts from those which are more automatic and involuntary. However, with the recognition that much of the activity of the human brain is automated, including the decision-making processes (Kahneman's so-called 'system 1 and system 2', Kahneman, 2011) this dichotomy becomes less challenging (*Figure 1*).

The easiest way to understand dissociation is that it lies on a continuum between distraction (i.e. concentration on a stimulus to divert attention from something unpleasant) at one end, and reflex dissociation at the other (*Figure 2*). Patients are generally very familiar with the concept of distracting themselves with something pleasurable in order to cope with a less pleasing or uncomfortable thought or sensation (for example listening to music while exercising at the gym). Such control of directed conscious thought may be highly developed, for example in athletes or those who practice meditation, who may be able to control their awareness of physical discomfort or intrusive sensations very effectively.

An insight into the reflex or automatic nature that dissociation can manifest can be gained by considering what happens when we think about an event or issue in our lives that is embarrassing or shameful. This can be tried when alone, for example while driving. When a particularly embarrassing event in life is recalled, either by choice or inadvertently, quite automatically some action may be triggered to drive the thought out of consciousness – coughing, whistling, vocalizing, turning up the radio – in a manner which may surprise, and cause witnesses to ask what is wrong. This process is sometimes known as displacement, and can be seen as the mildest form of reflex dissociation.

On the most severe end of the spectrum lies the phenomenon of involuntary dissociative attacks, which are the commonest type of psychogenic non-epileptic seizures. In such patients, there is a powerful and automatic switching of attention away from an aversive thought, memory or emotion, often associated with traumatic or abusive memories that might otherwise appear in conscious thoughts as 'flashbacks'. Switching attention away from these thoughts can be considered protective, as it prevents

CASE STUDY: PART 3

The patient and her mother are told that the attacks do not look particularly like epilepsy, and that non-epileptic seizures are a much more likely diagnosis. The relationship between these attacks and a history of psychological trauma, i.e. things that have happened to the patient outside their control which are intolerable or unacceptable, is discussed. The mother discloses that there have been family problems for some years, and that she is estranged from her ex-partner who was recently found to have been sexually abusing her daughters. This has been reported to the police and enquiries are now underway.

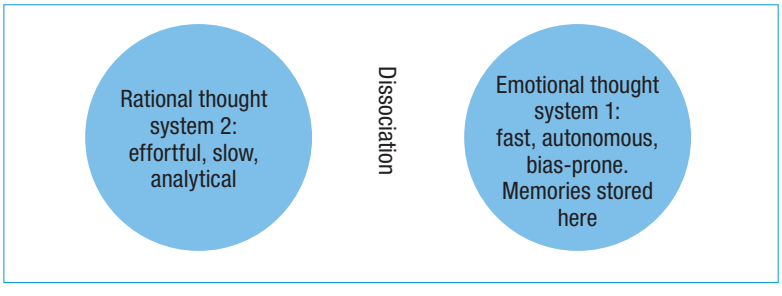

Figure 1. The process of dissociation can be seen as an involuntary (reflex) separation of rational thought (system 2) from emotional thought (system 1) as a psychological defense mechanism in response to traumatic memories.

Figure 2. The spectrum of dissociation severity. At the mildest end lies volitional distraction. Displacement may occur involuntarily, especially in response to uncomfortable or embarrassing memories. Dissociation may occur to suppress thoughts and memories which are intolerable.

the subject from re-experiencing distressing thoughts and emotions (although some echo of the provoking trauma may remain in the physical manifestation of the dissociative attack, such as trembling, side-to-side head movement, pelvic thrusting or fighting movements). The emotional nature of the events may also be evident from the distressed state of the patient after the attack (although the patient characteristically describes this as a response to the unpredictability and impact of the blackout itself).

It follows from this concept that dissociation is a common and natural response of human beings to a variety of aversive experiences, thoughts and memories that we encounter in life, and does not generally accompany a mental illness. Instead, it can be seen as an adaptive and compensatory response to trauma which helps maintain psychological stability following otherwise intolerable life events which leave a permanent mark on memory.

Communication with the patient after diagnosis

Most patients will accept a reasonable explanation and will acknowledge, sometimes tacitly and sometimes overtly, the significance, if any, of trauma in their own life story (*Case study: part 4*). Such patients may welcome the opportunity to talk and explore the issues. Indeed, a disclosure of trauma may represent the first step on the pathway of healing for them. While it is not usually appropriate in clinic to question patients about details of traumatic events in their lives, acknowledgement that psychogenic non-epileptic seizures are often associated with trauma, explanation of what psychological trauma is and provision of an opportunity for the patient to acknowledge or deny the relevance to his/her own situation is very important. If traumatic issues are volunteered, sympathetic acknowledgement and facilitation of further disclosure is appropriate. Whatever is disclosed, a history suggestive of psychogenic non-epileptic seizures should trigger awareness in the clinician that there may be issues of safeguarding to consider immediately, especially if the patient is vulnerable or in an abusive relationship (*Case study: part 5*). Questions about patients' safety within their relationships are therefore appropriate.

A substantial minority of patients with an unequivocal diagnosis of psychogenic non-epileptic seizures vigorously deny trauma. This group is not well understood, but an initial denial of trauma may mean that the patient does not want to disclose, acknowledge or discuss a painful event in his/her past, that he/she believes that he/she has dealt with the emotional fallout of an issue and put it behind him/her, or that the patient has become so habituated to the emotional impact that he/she no longer sees it as traumatic. Feelings of low self esteem, shame and guilt act as further barriers to disclosure of traumatic life events. Traumatic events may be disclosed only in psychotherapy, and even then after many sessions. There is, however, a substantial minority of patients where no history of trauma is evident despite psychotherapy (in the author's experience, about 10–20%).

CASE STUDY: PART 4

The patient and her mother are told that in view of the disclosed issues it is most likely that the diagnosis is one of psychogenic non-epileptic seizures, and a brief explanation of the way in which dissociative seizures protect victims of trauma from disturbing memories and emotions is offered. They are reassured that serious injury is extremely unlikely during these attacks and that they need not call an ambulance for assistance unless the patient has an obvious injury. A referral to the local epilepsy service is offered for confirmation of the diagnosis and for psychotherapy support during the police investigation and treatment.

CASE STUDY: PART 5

The patient was reviewed in the neurology unit and the diagnosis confirmed. By the time of the appointment her attacks had become very much less frequent and she appeared less distressed. She disclosed a history of rape and sexual assault going back many years that she had been unable previously to disclose because of threats of violence from her mother's ex-partner directed to her and her sisters.

Clarity in the diagnosis and admission by the clinician of the extent of uncertainty is important. No diagnostic term is universally accepted and all have drawbacks. The term 'dissociative seizure' is defined in the *International Classification of Disease*, 10th Revision and is probably the best, although not the most widely understood. Patients may feel the term 'psychogenic' is pejorative, and the term 'non-epileptic' states what the seizure is not, rather than what it is. Patients or carers may complain that their symptoms have not been properly assessed, that they are not listened to or that important evidence of the organic nature of the events has been ignored.

The potential benefits of psychotherapy should be discussed, and the implications that such symptoms do not require antiepileptic drugs broached. Precise diagnosis, drug management and referral for psychotherapy are probably most appropriately undertaken from a specialized clinic.

The skills required for delivering an acceptable diagnosis of psychogenic non-epileptic seizures are acquired with practice (Reuber, 2019). Where it is suspected, it is reasonable to introduce the possibility of psychogenic non-epileptic seizures early in the differential diagnosis of transient loss of consciousness (this is facilitated by an explanation of why they occur).

What to tell the carers

Patients, families and carers may challenge the diagnosis and express reasonable concern about the possibility of serious injury or death during the attacks. First aid advice should be offered, including offering calm reassurance to the patient, removing the patient from sources of injury, and calling for help if there is evidence of serious injury. The patient and carers can be reassured that serious injury is very unusual in psychogenic non-epileptic seizures, and patients are not at risk of death unless by iatrogenic disaster. First aid does not necessarily require administration of

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oxygen during an attack (Dickson et al, 2019) as the problem is of lung ventilation rather than lung failure. It is unnecessary to summon an ambulance unless there is obvious physical injury. When paramedics attend, it is preferable to check for oxygen desaturation with a pulse oximeter before giving oxygen, as avoiding oxygen administration averts reinforcing the idea that urgent medical attention is required for each seizure.

Visits to accident and emergency departments with such seizures are often particularly unpleasant for those with the condition. Empathy is most important, and a clear, unequivocal acceptance that the attacks represent an illness as real as epilepsy and just as significant.

Mood disorder, somatization, personality disorder and self-harm

A common clue to the emotional nature of a seizure disorder is the coexistence of psychopathology, such as mood disorder, somatization, personality disorder and self-harm (van der Kolk et al, 1994; Reuber et al, 2003). Mood disorders and somatization are commonly seen in people who have experience of protracted high levels of stress, sometimes in the distant past. Personality disorder, especially borderline personality disorder, can be associated with experiences of abuse, and self-harm is often an indicator of low self-esteem. Rather than seeing these issues as separate and discrete illnesses visited upon them, patients may benefit from understanding that they are all linked by their personal life experiences. Psychotherapy can be invaluable in joining up the pieces of the jigsaw for each patient.

Malingering and factitious disorder

Feigning seizures in order to avoid personal obligations and duties happens occasionally (indeed is described by Fyodor Dostoevsky in his classical novel 'The Idiot'). Factitious disorder, that is the deliberate feigning of an illness in order to adopt a sick role, is uncommon among people with psychogenic non-epileptic seizures, but its prevalence is difficult to determine. Clinicians' knowledge of the condition relies heavily on case series. It is difficult to diagnose, relying on recording of occurrences that are incompatible with the patient's claims. The condition frequently evades diagnosis for years. It is probably more common in those with more severe disability.

It is reasonable to suspect the diagnosis in patients with medically unexplained symptoms where inconsistencies are noted between the patient's behaviour and what the patient tells medical attendants.

Management of the condition is difficult, contentious and highly specialized. It carries a significant mortality risk.

Role of psychological therapy

Although a Cochrane review in 2014 found no reliable evidence of benefit of psychotherapy (Martlew et al, 2014) there have been attempts at randomized trials of psychotherapy for psychogenic non-epileptic seizures, which support the notion that psychotherapy is valuable, with reduced seizure frequency and improved quality of life found (Goldstein et al, 2010; LaFrance et al, 2014) and that it is probably very cost-effective (Reuber et al, 2007). Evidence of decreased health-care utilization as a result of psychotherapy is awaited.

In contrast to the published evidence, the majority of patients report profound benefits of psychotherapy, especially to stabilize mood, to provide techniques for grounding to avert seizures and to help address issues of trauma that have left lasting aversive memories. The evidence that psychotropic medication is helpful is less convincing.

Management of acute psychogenic non-epileptic seizures

Psychogenic non-epileptic seizures commonly present as emergencies, and suspicion of the diagnosis may be high because of the clinical presentation or because an appropriate expert has already made the diagnosis. Psychogenic non-epileptic seizures do not respond readily to benzodiazepines or other medication, and the high doses required to suppress dissociative movements may cause respiratory depression. It is therefore understandable that patients presenting with 'pseudostatus epilepticus' not infrequently end up paralysed and ventilated on intensive care units. Every effort should be made to avoid this outcome, and pulse oximetry should be used before administering benzodiazepines if possible.

The ideal management of a non-epileptic seizure involves grounding (i.e. attempting to communicate with the patient by assertive, rational speech, touch) and calm reassurance. Some patients may respond to mild aversive stimuli (for example smelling salts).

Conclusions

Psychogenic non-epileptic seizures are commonly encountered in clinical practice in the emergency room. Diagnosis is challenging, but should be considered in the differential diagnosis of seizures and status epilepticus. Dissociative seizures must be seen as involuntary and usually part of the range of psychological reactions to trauma. If the diagnosis is a possibility, issues of child or adult safeguarding should be immediately considered. Accurate diagnosis depends on the recording of a seizure, often on a mobile telephone, and the assessment of the recording by an expert. Treatment with psychotherapy improves wellbeing and lessens health-care utilization at modest cost. **BJHM**

Conflict of interest: none.

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KEY POINTS

- Non-epileptic seizures are one of the three commonest causes of transient loss of consciousness (the others being epilepsy and syncope).
- There is a strong association between experiences of personal psychological trauma (e.g. experiences of physical, sexual or emotional abuse) and the development of non-epileptic seizures.
- Most of such seizures are dissociative. Dissociation can be understood as lying at one end of a spectrum of human responses to aversive thoughts with purposeful distraction at the mildest end and reflex dissociation at the most severe.
- Dissociation protects traumatized individuals against the adverse effects of traumatic memories on their mental health.
- Non-epileptic seizures often respond favourably to tailored psychotherapy.
- Rarely non-epileptic seizures are a feature of malingering. Identifying these patients and managing them out of the health-care system is difficult and highly specialized.