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Peri-ictal behavioural change in people with an intellectual disability

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ABSTRACT

The purpose of this article is twofold. Firstly we review the knowledge on peri-ictal behaviour change and its importance in people with an intellectual disability. Secondly we explore methods of identifying peri-ictal behaviour change in people with an intellectual disability through data from a pilot project. The literature search identified a clear association between seizure activity and behaviour change in people with epilepsy and no intellectual disability; but for people with intellectual disability research is scarce and conflicting. The pilot project provided data on three individuals. This showed behavioural inconsistencies from one month to the next independent of seizure activity. There is a sparsity of research on peri-ictal behaviour change pertaining to individuals with intellectual disabilities and epilepsy. Further research into this area is needed to clearly ascertain the presence (or not) of an association between epilepsy and behavioural changes in people with intellectual disabilities. Novel methodology specific to people with an intellectual disability should be considered. One such methodology would be an extended period of descriptive analysis in the form of a prospective single case design.

1. Introduction

Behavioural changes, both real and imagined, have been recognised in association with epilepsy since antiquity (Masia and Devinsky, 2000). The pervasive negative portrayal of behavioural changes in people with epilepsy (PWE) has caused stigmatisation and led many to hide their disorder (Masia and Devinsky, 2000).

Recent research has shown an association between the presence of active epilepsy and behavioural change (Kanner, 2001; Silberman et al., 1994). Peri-ictal behavioural and cognitive changes cause disability and distress in PWE; despite this they are poorly investigated and recognised (Boylan, 2002; Mula and Monaco, 2011). Epilepsy is common and severe in people with intellectual disabilities (PWID) (Espie et al., 2012). Peri-ictal changes are of increasing interest in terms of behavioural change yet are poorly understood in PWID (Boylan, 2002).

2. The phases of peri-ictal change

The peri-ictal period refers to a period of days before and after a seizure (Boylan, 2002). It consists of pre-ictal, ictal and post-ictal periods (Boylan, 2002). Research has demonstrated major and prolonged changes in motor cortex excitability in the pre and the postictal period (Badawy et al., 2009). This is in keeping with the growing body of evidence that supports that seizures begin and end after we initially thought (Boylan, 2002).

2.1. Pre-ictal period

The pre-ictal period consists of two distinct entities epileptic auras and prodromes. Epileptic auras are ictal events manifesting as alterations in subjective perception and mostly occur several seconds up to a few minutes before seizure onset (Maiwald et al., 2010). They include formed images, humming, buzzing, irritability, jamais vu, time distortion, affective changes (Silberman et al., 1994); also insomnia, fearfulness, headaches, elation, emotional distress, epigastric sensations and some patients call out a warning of an imminent seizure (Boylan, 2002). Prodromes are sensations preceding a seizure by a period of hours to days (Maiwald et al., 2010). They are often associated with detectable surface EEG change (Mula et al., 2010). They may present as increased irritability, apprehension, mood lability, depression, psychosis, and directed aggression any of which may last several minutes, hours or days before a seizure (Marsh and Rao, 2002). Pre-ictal symptoms may wax and wane, but generally escalate up to the time of the seizure (Marsh and Rao, 2002).

Up to 29% of PWE report prodromal sensations more than 30 min prior to seizures; despite this the significance of prodromes is poorly understood (Maiwald et al., 2010; Marsh and Rao, 2002). Research has repeatedly identified BOLD (blood oxygen level

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dependent) fMRI changes occurring several minutes before seizure onset (Baumgartner and Aull-Watschinger, 2005). The process of ictogenesis therefore probably evolves over minutes or hours and involves a spatially distributed neuronal network with a complex interplay of excitatory and inhibitory processes (Baumgartner and Aull-Watschinger, 2005).

2.2. Ictal period

Behavioural changes and psychopathology may be seen during the ictal period (during an ictal EEG discharge) especially in association with simple and complex partial seizures (Lancman, 1999).

Ictal psychiatric disturbances include – anxiety, intense feelings of fear or horror, panic attacks, depressed mood, tearfulness, sexual excitement, paranoia, hallucinations, illusions, laughter, forced thoughts, obsessions, déjà vu and other memory experiences, confusion, aggression/violence (Marsh and Rao, 2002). They are more commonly associated with seizures originating from the frontal and temporal lobes (Adachi et al., 2000; Swinkels et al., 2005).

2.3. Postictal period

The term postictal describes changes in behaviour, motor function and neuropsychological performance that may arise immediately after a seizure, or be delayed in onset, and last seconds to days (Boylan, 2002; Remi and Noachtar, 2010). The postictal period leaves a trail of altered brain function (So and Blume, 2010). It is likely that the emergence of postictal behavioural change is related to the brain's homoeostatic response to seizure and continued non-convulsive epileptic discharges (Boylan, 2002; Elliott et al., 2009). There are many types of behavioural change in the post ictal period, some of which are noted below.

Post ictal aggression may be acute in onset (occurring several minutes after a tonic clonic seizure when the patient is confused) or sub acute (occurring hours to days after a seizure) (Gerard et al., 1998; Yankovsky et al., 2005). Sub acute post ictal aggression is rare (Gerard et al., 1998; Yankovsky et al., 2005).

PIP (Post Ictal Psychosis) is characterised by an episode of psychosis occurring within one week, after a seizure (Morrow et al., 2006). The concept of PIP was introduced in the 19th century but it was not established as a clinical entity until the 1990s (Oshima et al., 2006). Lishman believed PIP to be an extension of the post-ictal confusional state with clouding of consciousness or at least amnesia for the episode as a key characteristic (Prendergast et al., 1999). More recently it has become accepted that patients frequently have no evidence of clouded consciousness, as supported by Logsdail and Toone's definition (Joshi et al., 2006; Prendergast et al., 1999).

PIP is common, accounting for approximately 25% of psychoses in epilepsy and may be associated with profound morbidity (Morrow et al., 2006; Prendergast et al., 1999; Trimble et al., 2010). It generally follows an exacerbation in seizure frequency or intensity and emerges after a lucid interval (Akanuma et al., 2005). In certain populations, e.g. PWID, PIP can cause very difficult management problems; recognition of the condition is important (Trimble et al., 2010). The duration of PIP ranges from 1 to 90 days and is likely to be longer in PWID (Trimble et al., 2010).

Postictal headaches are prevalent, moderate to severe in intensity, last many hours and frequently have characteristics of migraine; they impinge on patient quality of life (Ekstein and Schachter, 2010).

Depressive postictal symptomatology is relatively common in patients with treatment resistant epilepsy; it arises in approximately 50% of patients and has a median duration of 24 h, but can last up to two weeks (Kanner et al., 2010; LaFrance et al., 2008). Postictal depression describes a period of depressive symptomatology that typically occurs within 5 days of a seizure and lasts more than 24 h (Kanner et al., 2010). It may arise immediately after a seizure but more typically occurs after a latent symptom free period and rarely meets the criteria of DSM IV (Kanner et al., 2010).

Postictal anxiety occurs in 45% of patients with a median duration of symptoms of 6–24 h (Mula et al., 2010).

Postictal manic symptoms arise in approximately 22% of PWE, some authors have made close associations between post ictal mania and PIP (Kanner et al., 2010; Mula and Monaco, 2011; Mula et al., 2010). Typically post ictal mania presents with racing thoughts and excessive energy lasting on average 2 h (Kanner et al., 2010).

3. Peri-ictal behaviour change in PWID

The importance of being aware of functional and behavioural consequences of epilepsy in PWID is cited in the literature and acknowledged by Psychiatrists working in the field (Espie et al., 2012). Turky et al. (2008) concluded that children with cognitive impairment and severe epilepsy were at higher risk of developing behavioural and emotional problems. It is also recognised that post-ictal psychosis can be difficult to manage and of longer duration in PWID (Trimble et al., 2010).

Publications in this area concentrate on a specific phenomena occurring either pre or post-ictally (e.g. post or pre-ictal affective changes (Kanner et al., 2010; Marsh and Rao, 2002)). There is little literature relating to the study of behavioural changes in the peri-ictal period for PWID. Bonaventura et al. (2006) reported peri-ictal neuroimaging findings of a patient with Fragile X Syndrome in status epilepticus. Clinical practice recognises the importance of ictal behavioural change, especially fluctuation in conscious level associated with Non-Convulsive Status Epilepticus.

Research has concentrated on establishing if PWID and epilepsy, on average present with greater behavioural disturbances than PWID and no epilepsy. Little distinction has been made between inter-ictal and peri-ictal periods in previous research relating to PWID and epilepsy.

4. Behaviour change in people with intellectual disabilities (PWID) and epilepsy

Behavioural problems in PWID have long been considered a major impediment to successful and sustained community placements and general adjustment (Grizenko et al., 1991). A widely accepted definition is provided by Emerson (2001) “Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.”

The causation of behavioural change is complex including communication problems, the nature of the cognitive impairment and the presence of psychiatric pathology. Independent of the presence of epilepsy, PWID are more likely to develop a psychiatric disorder than those without (Smith and Matson, 2010). It is postulated that underlying neurological damage, causing ID, may affect behaviour and emotional responses (Grizenko et al., 1991). Associated brain damage may also cause changes and abnormalities in perception, discrimination and the ability to abstract, leading to concrete coping mechanisms (Ghaziuddin, 1988). Additionally environmental factors may pose challenges and threats that exceed the patient's comprehension and ability to adapt, all which contribute to the presentation of behavioural challenges (Grizenko et al., 1991). PWID can also differ from the rest of the

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