Complexities of diagnosis & treatment of people with epilepsy & learning disability

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- Complexities of Assessment
- Differential Diagnosis
  - Physical health conditions
  - Mental health and behaviour
- Video clips 

- Complexities of Treatment
- Case examples
- Key Points

Epilepsy in LD

- adults with LD make up a significant proportion of the population with epilepsy
- 40% of adults with LD in Glasgow have a history epilepsy
- many of them have at least one other chronic physical or mental health condition
- many are on multiple medications
- most will have some form of communication impairment

Assessment

- Challenges
  - Accessing clinic appts
    - waiting & appt times
    - busy clinic setting
    - home visit can be much more successful but is not always an option

  - Communication
    - it is much more difficult for someone with LD to explain their experience
    - they may be able to do so with more time or the use of communication aids
    - sometimes the clinician has to rely solely on the history provided by others

Assessment

- Challenges
  - Gathering information from others
    - different carers can give differing information
    - need to know exactly what happens, how it starts, how long it lasts, what happens afterwards, where & when it happens and any triggers such as stress, medication changes, fever or other physical ill health
    - different carers may have very different views on the impact of a persons epilepsy
    - seizure recordings can be very helpful
    - simple video can also help
    - Community Learning Disability Teams can support carers with gathering this information before clinic attendance

Investigations

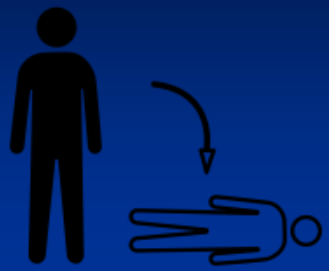
- people with LD should get access to the same investigations as everyone else
- can be difficult for people with LD to cooperate with – but with reasonable adjustments most can be achieved
- concerns about capacity to consent can influence decisions made
- results can be more difficult to interpret

Differential Diagnosis

- particularly difficult in LD due to high prevalence of other health problems

- Stereotyped behaviour problems are often misdiagnosed as epilepsy
  - Sudden aggression
  - Repetitive movements
  - Vacant staring

Differential Diagnosis



- Syncope (faint)
  - very common
  - misdiagnosed as epilepsy as often include some body jerks
  - can be cardiac related
- Migraine

  - more common in people with epilepsy
  - episodic and can include speech changes and visual disturbance
  - development of symptoms tends to be over minutes rather than seconds as occurs in seizures
- Hypoglycaemia (low blood sugar)
  - episodes often include odd behaviour and impaired awareness
  - most likely to occur in those with diabetes or fasting

Differential Diagnosis

- Hyperventilation/other respiratory phenomena
  - breath holding attacks
- Sleep disorders
  - night terrors/nightmares/sleep walking/confusional arousals
  - REM behaviour disorder
- Movement disorders
  - tics & dystonia
  - paroxysmal dyskinesia

- Gastroesophageal reflux with posturing
  - involuntary twisting and writhing movements, eye deviation
  - events tend to occur in sleep or after meals
  - often associated with recurrent vomiting

Differential Diagnosis

- Psychogenic non epileptic attacks
  - a sudden, usually disruptive change in a persons behaviour, perception, thinking or feeling which is usually time limited and resembles or is mistaken for epilepsy but which does not have the EEG changes that accompanies a true epileptic seizure
  - thought to be related to the psychological and emotional state of the patient
  - can occur alongside epilepsy
  - best managed with psychological interventions
- Panic attacks/anxiety
  - can be missed if person unable to describe their anxiety/fears
- Psychotic experiences
  - hallucinatory experiences can be mistaken for epilepsy but other psychotic symptoms are usually apparent

Differential Diagnosis

- Stereotyped behaviour
  - most common in autism and profound learning disability
  - can include hand flapping, finger movements, body rocking
  - sometimes appear as if they are not fully aware

- Episodic dyscontrol
  - rage attacks, emotional outburst or bursts of aggressive behaviour
  - often in response to minor stimuli – or no apparent stimuli
  - tend to be longer in duration & less stereotypical movements

- Non-epileptic staring spells (day dreaming)
  - often misdiagnosed as absence seizures
  - tend to be longer and the person can usually be distracted out of it

Tonic Clonic

Tonic

Absence

Focal with impaired awareness

Panic Attack

Stereotypic Behaviour in Autism

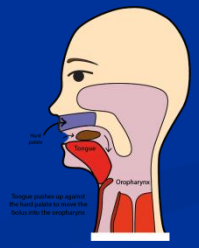
Stereotypic Hand Movements in Rett Syndrome

Behaviour & Psychiatric Problems in LD

- epilepsy, behaviour problems and psychiatric symptoms often occur together
- mood & behaviour changes can occur before, during & after seizure activity
- epilepsy drugs can cause depression, psychosis & behaviour problems
- epilepsy drugs can be used to treat mood, anxiety & aggressive behaviour
- some reports that an improvement in seizure control can lead to a deterioration in behaviour

Medication

- decision to introduce medication is a balance between the potential medication side effects and an assessment of the impact of seizures on:
  - the individual
  - family/carers
  - behaviour and psychiatric disturbance
  - physical morbidity
    - swallowing
    - weight changes



Principles of Medication Use

- ensure appropriate first line treatment for seizure type and syndrome

- in patients continuing to have seizures
  - review diagnosis
  - review compliance
  - ensure maximum tolerated dose has been tried

2nd Drug Treatment Choice

- mode of action different from first drug
- beware of drug interactions
- likely cognitive or behavioural side effects

Common Side Effects

- Headache
- Nausea
- Vomiting
- Sedation
- Cognitive impairment (confusion, memory impairment)
- Ataxia (poorly coordinated movements & balance)
- Double vision

Assessment of treatment outcomes

- Seizure frequency
- Seizure severity
- Quality of life
  - Achieving seizure freedom at the cost of extreme sedation or immobility is not necessarily worthwhile
  - Focus on improving tonic clonic and atonic seizures rather than partial or absence seizures which tend to have less risks

Other Treatments

- Treatment options other than medication
  - surgery
  - vagus nerve stimulation
  - general health improvement – diet, sleep pattern, activity level, anxiety/stress management

Key Points

- always keep an open mind when assessing possible epilepsy & medication side effects in people with LD
- gather as much information as you can from as many sources
- people with LD should get access to the same investigations and treatments as everyone else
- epilepsy comes in various formats – as do the epilepsy imitators
- in LD, stereotyped behaviour or emotional disturbance is most likely to be misdiagnosed as epilepsy – but odd epileptic activity is also sometimes misdiagnosed as behaviour disorder
- medication can be life saving, but can also cause significant side effects - think carefully about the risks and aim for the best all round quality of life – treatment outcome is not just seizure frequency
- epilepsy can be more difficult to treat in people with LD – but that doesn't mean that we should be accepting poor outcomes for them