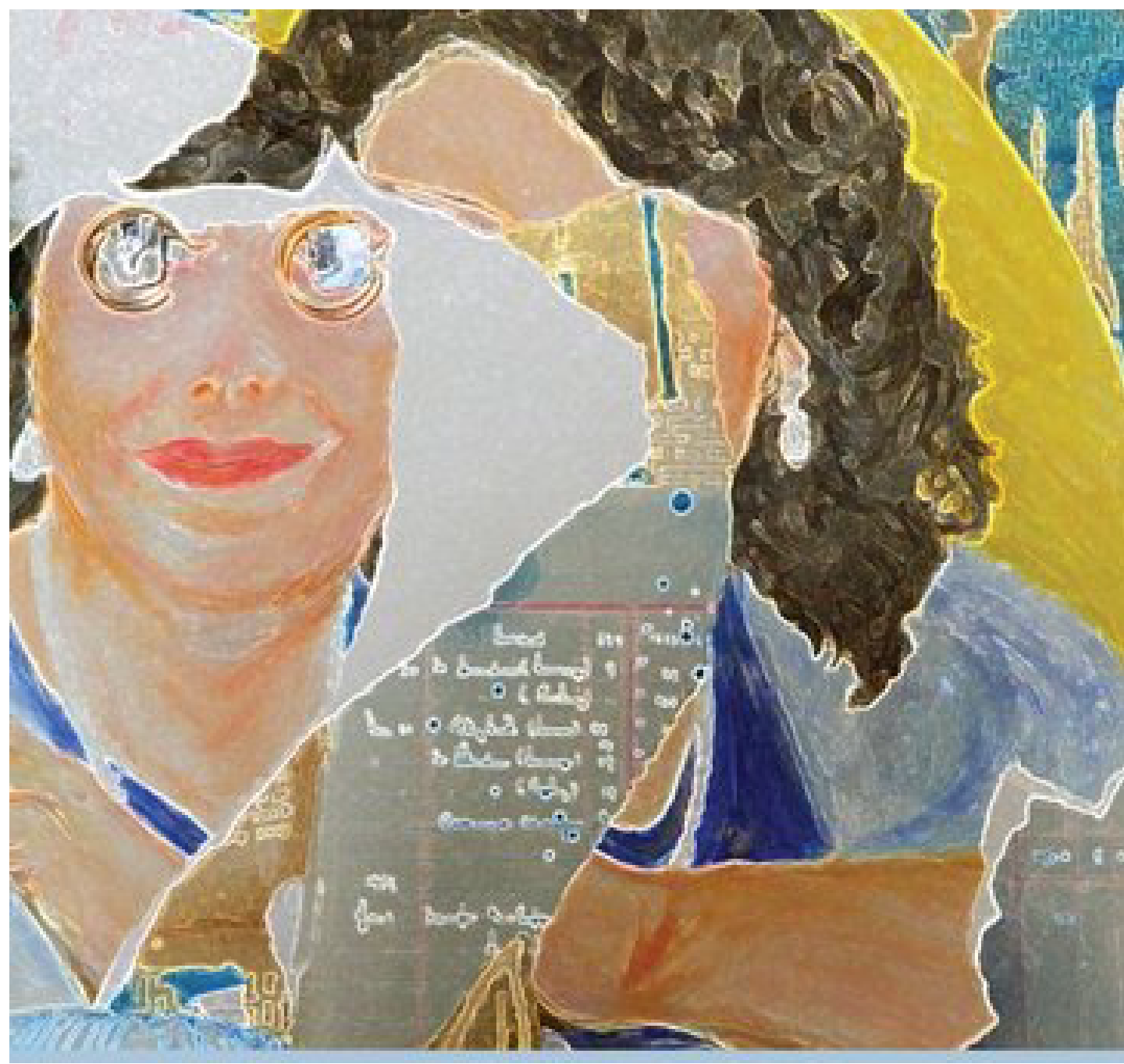




Experience



Inter and Intra-variability

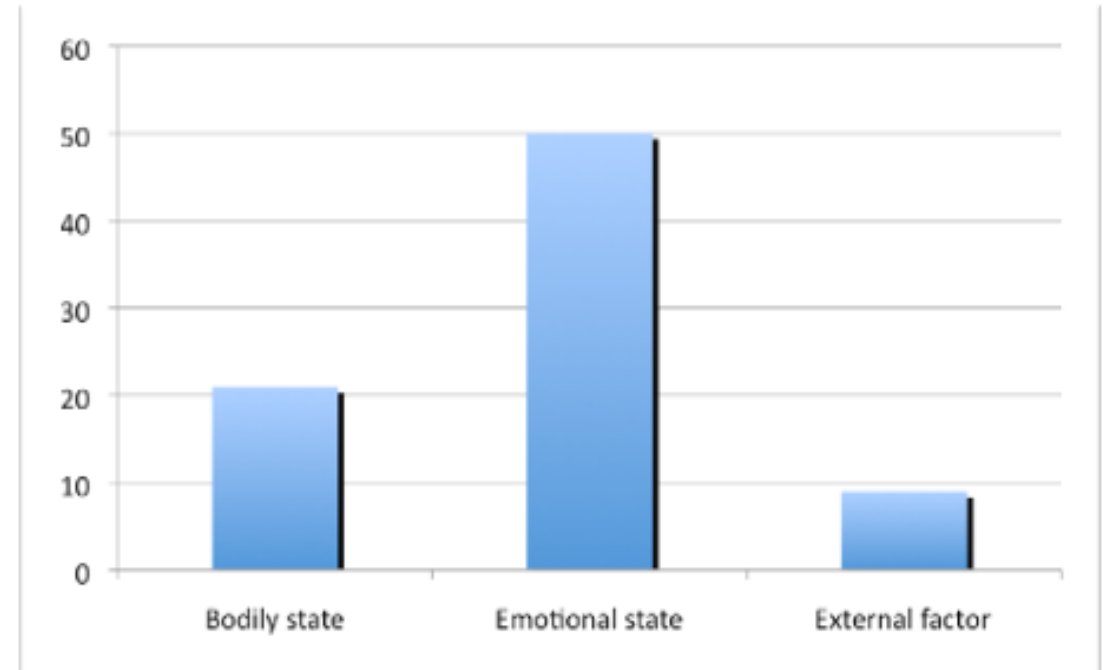
- Different people experience different symptoms (illustrated in co-occurrence network).
- Symptoms of functional seizures are not always the same.
- Symptoms change over time: example., patients initially experience panic attacks, but over time, symptoms of anxiety may diminish and manifestations of dissociation and functional seizures increase (Goldstein and Mellers, 2006).
- Table below taken from [Reuber et al., 2011](#)

Item	Always (%)	Frequently (%)	Sometimes (%)	Rarely (%)	Never (%)
(a)					
Triggers/warnings					
I am aware of a trigger for my attacks	10	4	44	9	31
My attacks are associated with emotional stress	8	9	47	13	23
My attacks come on when I am asleep	3	8	43	10	36
My attacks come on out of the blue without any warning	43	24	25	2	6

Triggers

Reuber et al., 2011 found considerable heterogeneity of triggers.

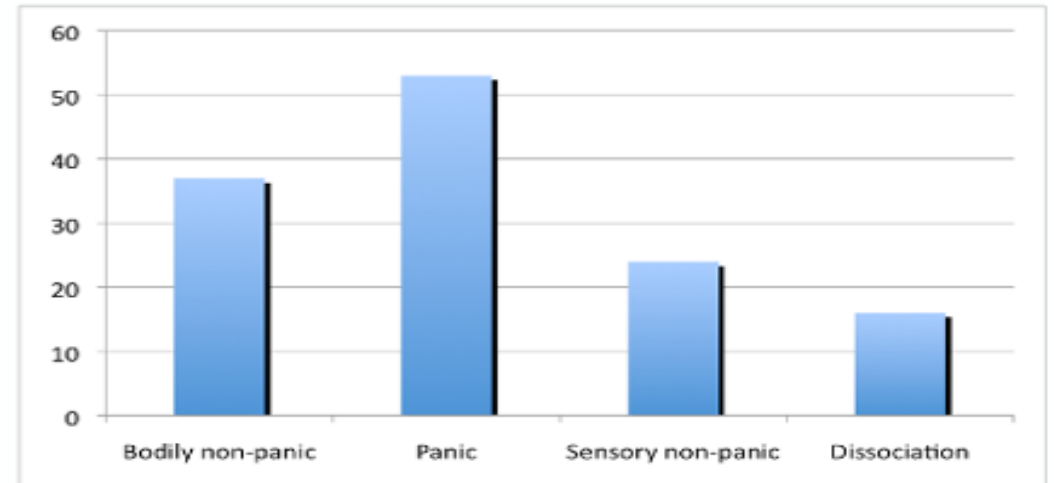
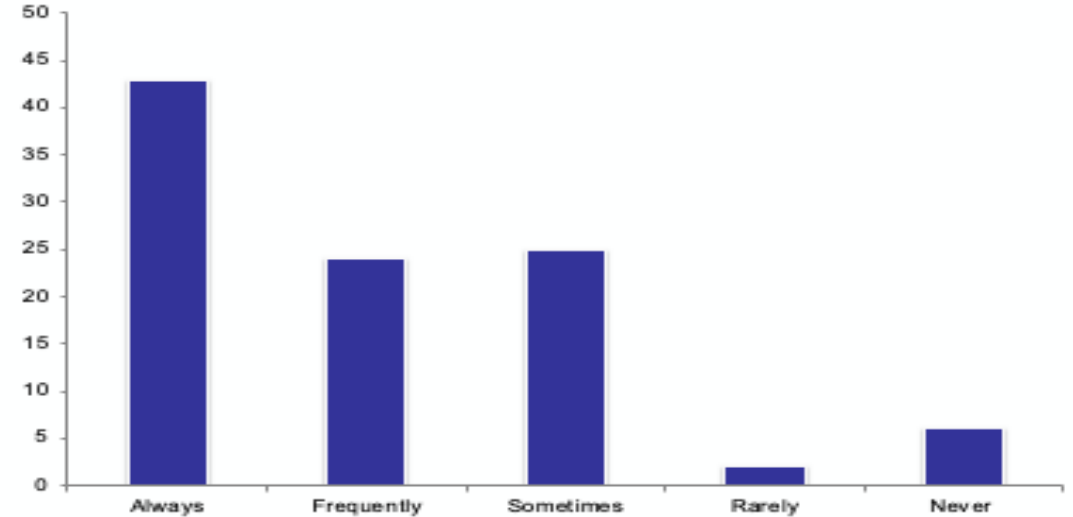
- Small minority (10%) were “always” aware of triggers; 57% were aware of triggers for some but not all; 31% claimed never to be aware of triggers
- 43% of patients stated that functional seizures “always” “come on out of the blue.
- Witnesses questioned in the same study reported being aware of seizure triggers more often than patients.
- plot is unpublished data



Warnings

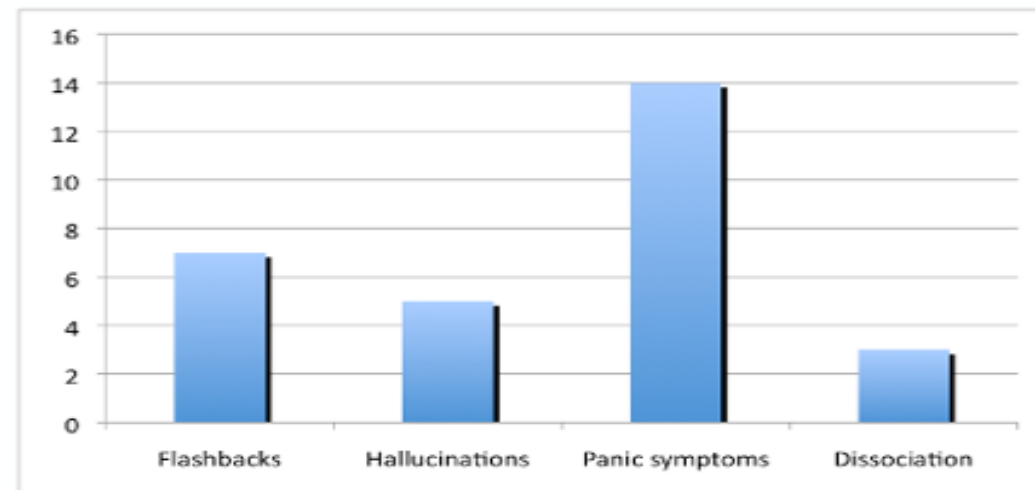
- rates of prodromal/warning symptoms vary widely (24%-92%, see Reuber & Rawlings)
- People are (at times) more aware of the physical warning signs as opposed to emotional warning signs.
- "Willful submission" (Stone & Carson, 2013). Although this does not mean the symptoms are intentional.

Plots taken from Reuber et al., 2011



Experiences during

- Tends to last longer than in epilepsy (Gates et al., 1985).
- functional seizures over 30 minutes occur in about one-third of patients.
- More than one-quarter diagnosed with PNES received intensive care treatment for presumed status epilepticus at least once (Reuber et al., 2003).
- Plots from Plug et al., 2009



Agent / force

seizures come, go, come in, come on, come up, creep up on you, get you



Event / situation

seizures happen, occur, take place, are due, start, finish, go on, develop, are experienced,



Space / place

drifting off, being off going, going off, being gone, coming back, coming round,



What does NEAD feel like?

"I feel like I am 'tripping' without taking anything. I am in another world short term, and I feel confused, dazed, disorientated and it's scary. My head and brain feel like a tin of broken biscuits. I am different and feel weird. Luckily these episodes don't last long, but they happen 'out of the blue', when you least expect it!"

"Understanding of my environment is lost, and my body changes with my eyes spinning and poor-coordination and my listening is affected. I feel stupid during these episodes and I wonder do people notice or think I am acting or faking it for attention?"

— People living with non-epileptic attacks

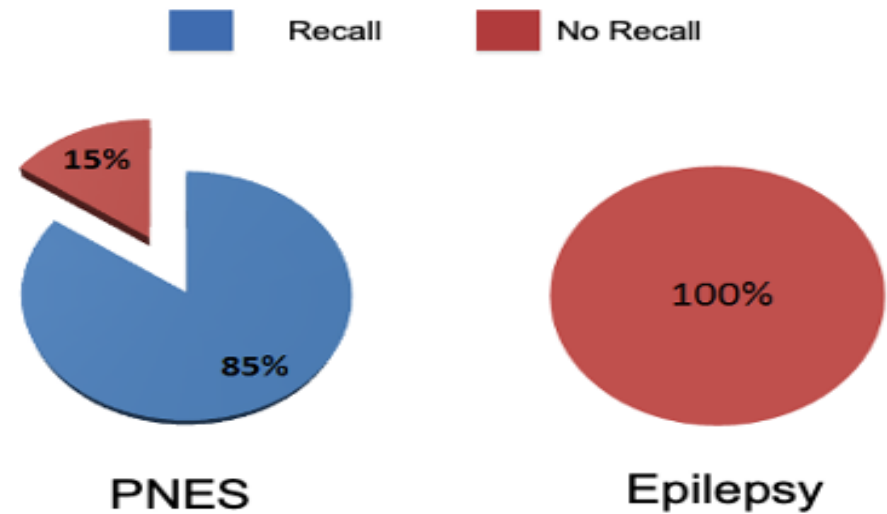
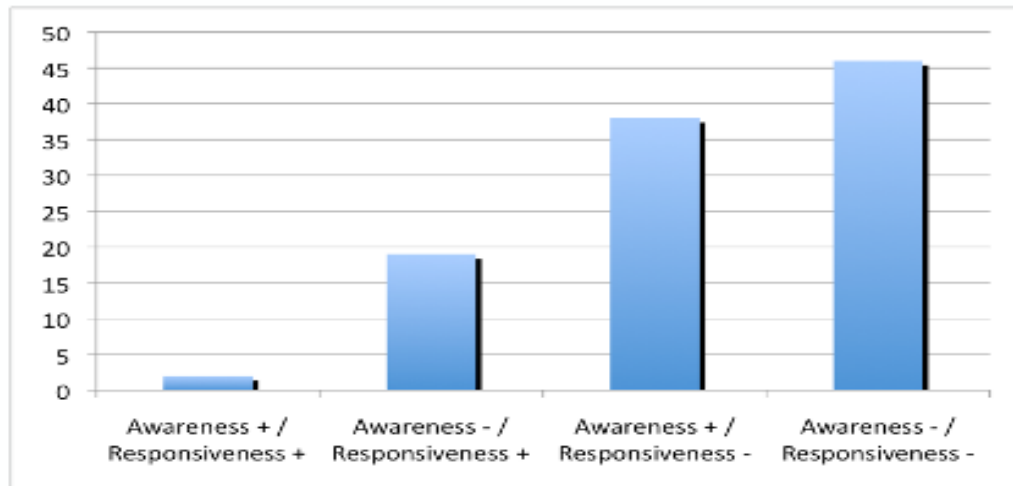
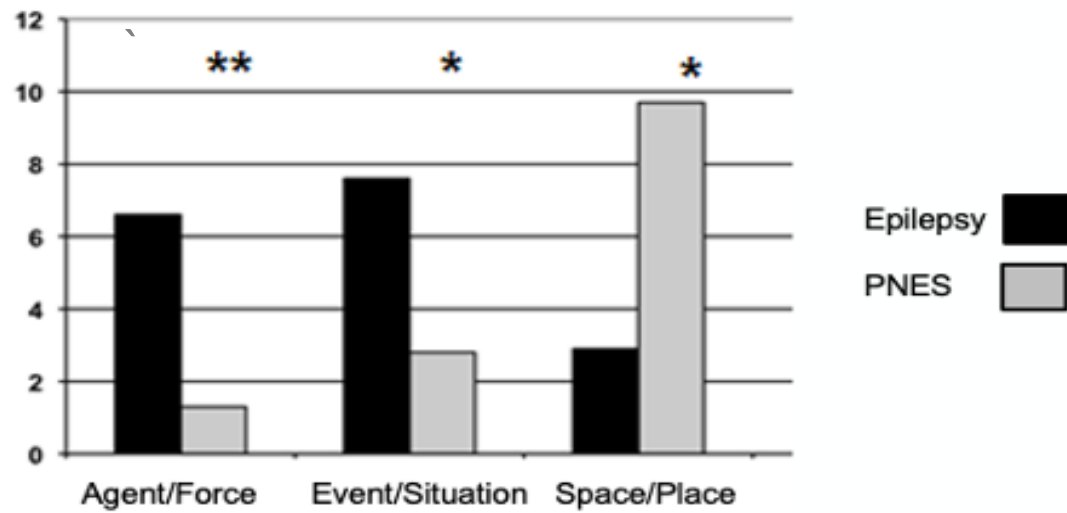
What does NEAD feel like?

“I feel really spaced out. Like I’m not really there. I try to move but I am like a snail. I try to talk but it’s like my tongue is stuck”

“I feel really spaced out. Like I’m not really there. I try to move but I am like a snail. I try to talk but it’s like my tongue is stuck”

“I really can’t get up and cannot speak, if I kick out it is not because I am being aggressive, it’s because my body can help it”

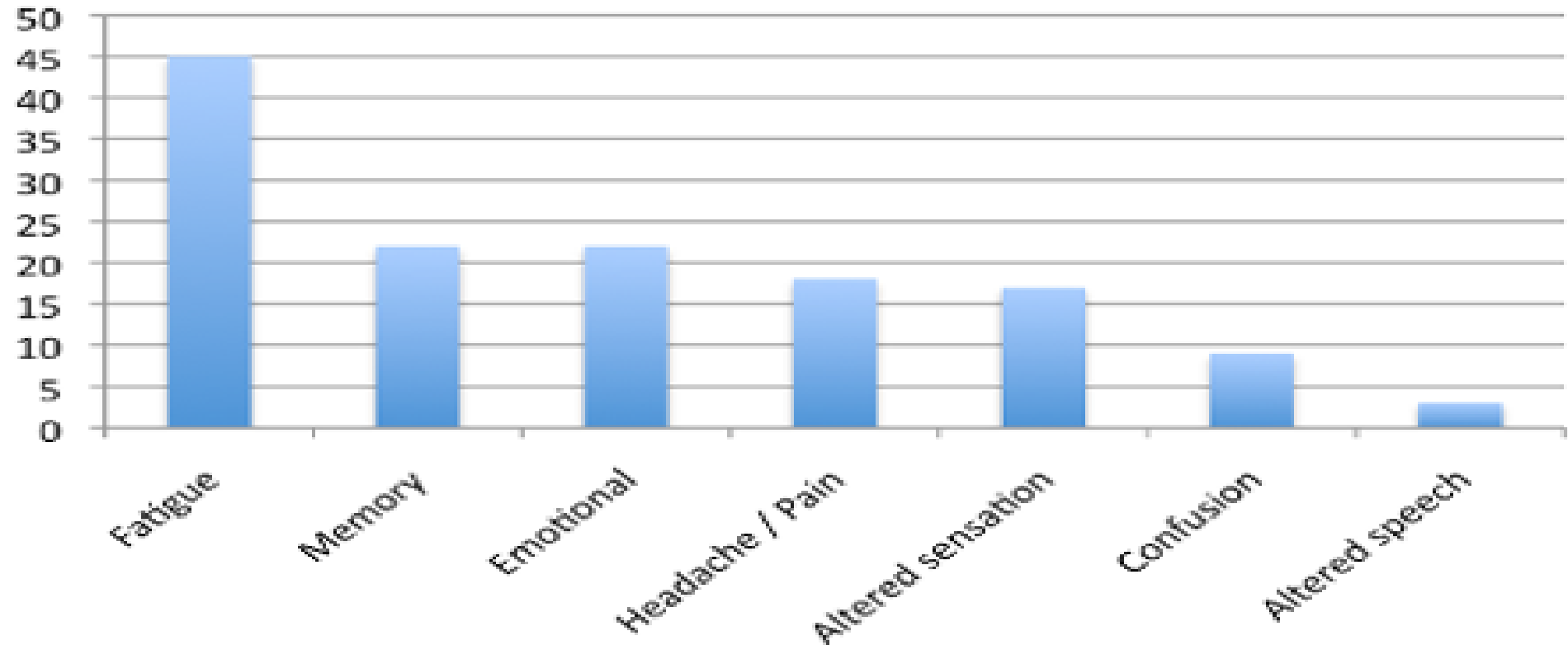
— People living with non-epileptic attacks



images via Reuber and Kurthen 2011 and Bell et al, 1998, and Kuyk et al., 1999

The aftermath

- Patients often find it easier to feel the post-ictal symptoms.
- Plot taken from...?



Experiences of professionals

- Review captured experiences of at least 3900 healthcare professionals from at least 63 different counties
- Responses demonstrated uncertainty about many aspects of NEAD
- NEAD considered challenging and frustrating
- Mixed views about who is responsible for treating patients with NEAD

Table 4 Key areas of research (concrete concepts) and cluster concepts

	Uncertainty	Understanding	Challenges & Frustration	Responsibility	Prognosis & Disability
Aetiology	✓	✓			
Terminology	✓	✓			
Perceptions of PNES	✓	✓	✓	✓	✓
Achieving, formulating and communicating the diagnosis	✓	✓	✓	✓	
Treatment: referrals, psychotherapeutic and pharmacological care	✓	✓	✓	✓	
Driving restrictions	✓				✓
Recommendations for change	✓				

PNES = Psychogenic nonepileptic seizures

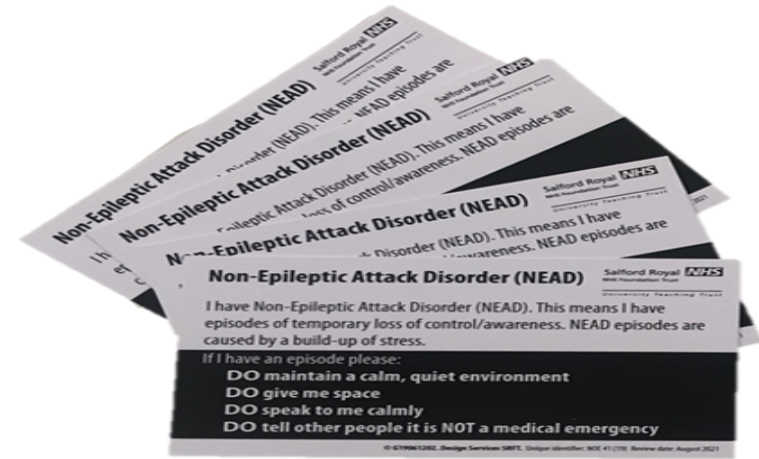
- How might this affect the care that people with NEAD receive?
- What could be the consequences of this?

Therapeutic Solutions

Is this NEAD?

- Salford Royal NEAD service guidance letter
- Friends/ family members
- Salford Royal NEAD guidance cards
- Medical alert bracelets

Do not attempt to make a differential diagnosis. If information about the diagnosis is not available, follow epilepsy guidelines.



Common concerns about NEAD

The changes that are experienced before, during and after episodes are caused by the fight/ flight/ freeze response

These changes might look and feel uncomfortable/ unpleasant but are not causing immediate harm:

- Brain activity remains the same
- Having an episode is not caused by and does not cause long-term internal damage.

Common concerns about NEAD

Risk of injury

- NEAD episodes do not cause internal damage
- Risk of injury from falls during episodes is low (number of injuries VS total number of episodes)

Duration of episodes

- Episodes can last seconds, minutes, hours or even days.
- Even if the episode lasts a long time (or longer than usual), it is still not causing internal damage
- The episode will pass naturally without need for medical intervention

Symptom variation

- Many people experience episodes that feel very different to one another
- It is normal for episodes to change over time

Do

1. Maintain a calm, quiet environment
2. Give me space, speak to me calmly
3. Tell other people it is NOT a medical emergency
4. Help to re-orientate (e.g. tell the person where and who they are, what is happening).
5. Offer water.
6. Encourage noticing what they can see/hear (e.g. count the number of circles/ red things).
7. Maintain a calm environment.
8. Encourage focus on slow, deep breaths.
9. Find out if there is someone who can help them to get home/ to a safe place?
10. Provide support to friends/ family.

Do not

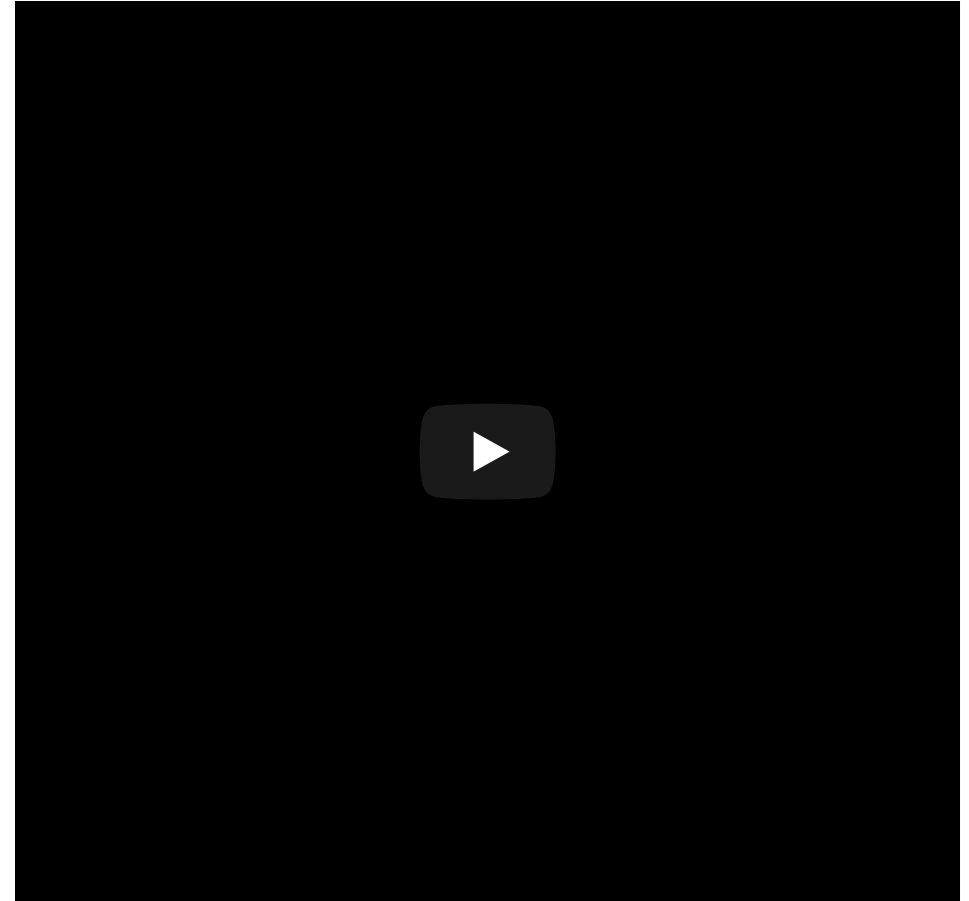
1. Give me medication
2. Touch me (unless to protect my head)
3. Crowd or stand over me
4. let there be more thn one person nearby
5. Try to bring me "out of it"
6. Restrain me
7. Time the episode
8. Take me to hospital, unless I have a significant injurt that needs immediate medical attention
9. try to lift the person up or try to get them moving before they are ready
10. Ask lots of questions

How we talk about NEAD matters

Communication has a significant impact on:

- Patient satisfaction
- Acceptance of the diagnosis
- Frequency/ severity of symptoms
- Future engagement with healthcare services

(Hall-Patch et al., 2010; McKenzie, Russell, Pelosi & Duncan, 2010)



How we talk about NEAD matters

“We know your symptoms are real”

“You do not have...”

“We do not think your symptoms are “all in your head””

“It’s nothing to worry about”

“We know that you are not pretending”

“You can control this”

“We know that this is not your fault”

“Stop doing this”

“NEAD is a well-recognised condition”

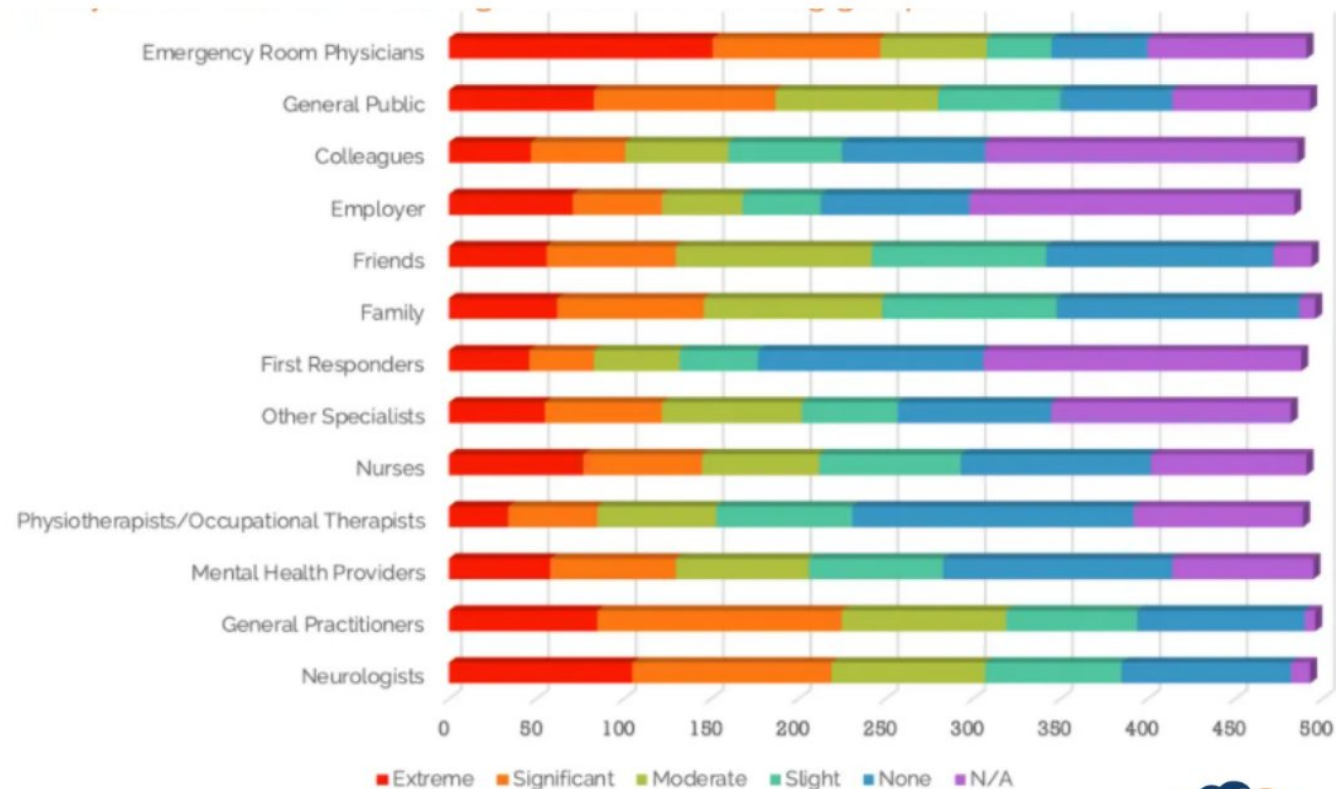
“It’s like having a software problem in your brain rather than a hardware problem”(Stone)"

“You are (just) stressed”

Stigma

FND RESEARCH

Have you felt Discrimination/Stigma from the following groups?



TOGETHER WE WILL SEARCH FOR BETTER
TREATMENTS THROUGH SCIENTIFIC RESEARCH



#FNDaware #FND2021 #LetsTalkFND

FNDHOPE.ORG

Case Vignettes

Case Example 1

You are called to an incident in a shopping centre. The report is of someone experiencing a sudden collapse. You arrive to find a man, approximately 50 years old, on the floor making jerking movements with his arms and legs. His eyes are closed and he is not responding to your questions.

Q: What are the standard assessments and interventions you would carry out in this situation?

,

Case Example 2

Whilst you are treating your patient, his care worker arrives. She lets you know that his name is Alan, he has a moderate learning disability, and has a NEAD diagnosis.

She tells you that he started to have NEAD episodes 3 years ago when he was living in an inpatient care facility. He was frequently restrained and sedated and did not understand why. His experiences were very distressing and, as a consequence, he now fears healthcare professionals.

Taking this information into consideration:

1. Q: *How might you change your approach?*
2. Q: *What might you do the same?*

Case Example 2 - "An Unhelpful Experience"

What could be done differently:

- Don't assume that I am drunk/ a druggie
- Don't assume that I am play acting for attention
- Do treat me with compassion – I am a person who is not in control and feeling very scared
- Don't tell me to get up, talk, stop burbling, telling me there's no reason why I can't talk
- Understand that the episodes can come in waves and I, like many people, can be thrown back in to another episode one after another for several hours
- Please offer me a drink with straw and then hold it – I am not able to move and, when episodes last for hours, can get pretty thirsty
- Do provide reassurance
- Do sit next to me, don't stand over me

Case Example 2 - "A Helpful Experience"

The most helpful things that the paramedic team did:

- They were calm
- They took on board all the information they could find in my bag and the lanyard
- They worked out that I could sometimes respond by nodding slightly and shaking head very slightly. They were quick to pick that up and the grunts I made! That made a massive difference.
- When I was in the ambulance the paramedic asked me if I wanted the straps on me kept on. I still couldn't talk or respond much but she seemed to understand that I could hear and understand. It was so helpful to keep the straps on because of my violent jerking. She was able to understand that I needed them staying.
- I can't remember if the paramedic asked me if I could hear her and understand her but I think she must have done.
- Paramedics explained my diagnosis to staff at the emergency dept.

Resources & Acknowledgments

Acknowledgments

- A big thank you to all of the Twitter community who contributed to this teaching through their very helpful suggestions.
- Many of these individuals were people who experience functional symptoms.



Website Links



FND Hope

- FND charity
- Lots of helpful information and resources for patients.



SRFT NEAD service

- NEAD service website
- Information and clinical resources for patients.



FND Society

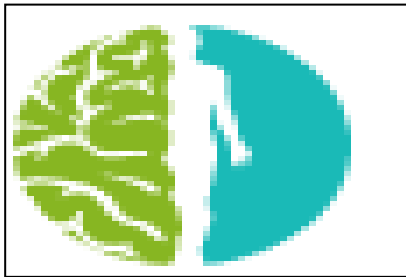
- Professional network for FND
- High quality teaching and educational material.

Website Links



FND Action

- UK Patient led charity for FND. Provides supports, support groups, informative website and advocating.



Neuro symptoms

- Informational website for patients and professions
- Lots of high quality resources and information sheets



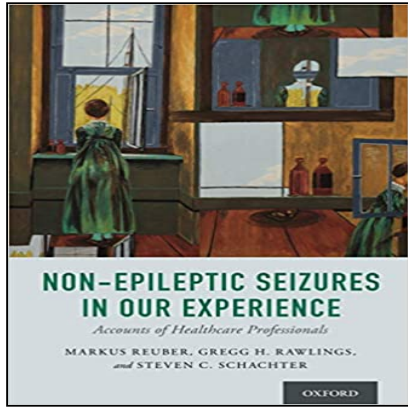
Non-epileptic attacks

- Registered trust and charity involved in supporting patients with non-epileptic attacks.

Books

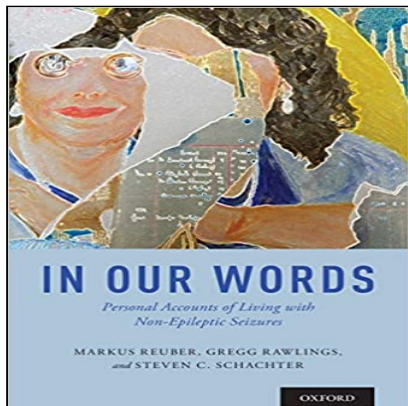
In Our Experiences

- Book collating professional experiences of working/supporting people with functional seizures.



In Our Words

- Book collating patient experiences of what it is like to live with functional seizures.



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