Functional Neurological disorders from a Neurologist's perspective:

What is wrong with our patients with 'nothing wrong with them'?

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“The most that can be expected from any model is that it can supply a useful approximation to reality: All models are wrong, but some are useful”

- George Box statistician

History

British VAD-nurse Claire Tisdall saw them coming in from the front: "I got quite used to carrying shell-shocked patients in the ambulance. It was a horrible thing, because they sometimes used to get these attacks, rather like epileptic fits in a way. They became quite unconscious, with violent shivering and shaking, and you had to keep them from banging themselves about too much until they came round again. Of course, these were the so-called milder cases; we didn't carry the dangerous ones. They always tried to keep that away from us and they came in a separate part of the train. They'd gone right off their heads. I didn't want to see them. There was nothing you could do and they were going to a special place. They were terrible."

Another nurse, Sister Mary Stollard: "They were very pathetic, these shell-shocked boys, and a lot of them were very sensitive about the fact that they were incontinent. They'd say, "I'm terribly sorry about it, Sister, it's shaken me all over and I can't control it. Just imagine, to wet the bed at my age!'"

What is the purpose of this talk?

- Present a model which explains the phenomenology of functional disorders which has face validity and is readily accepted by patients
- Help you understand why people develop the symptoms
- Explain a rational approach to treatment

The disorders of emotion regulation

Disorders of:

- somatosensory gating and
- disruption of the link between willing and executing movement

Psychogenic seizures (dissociative events)

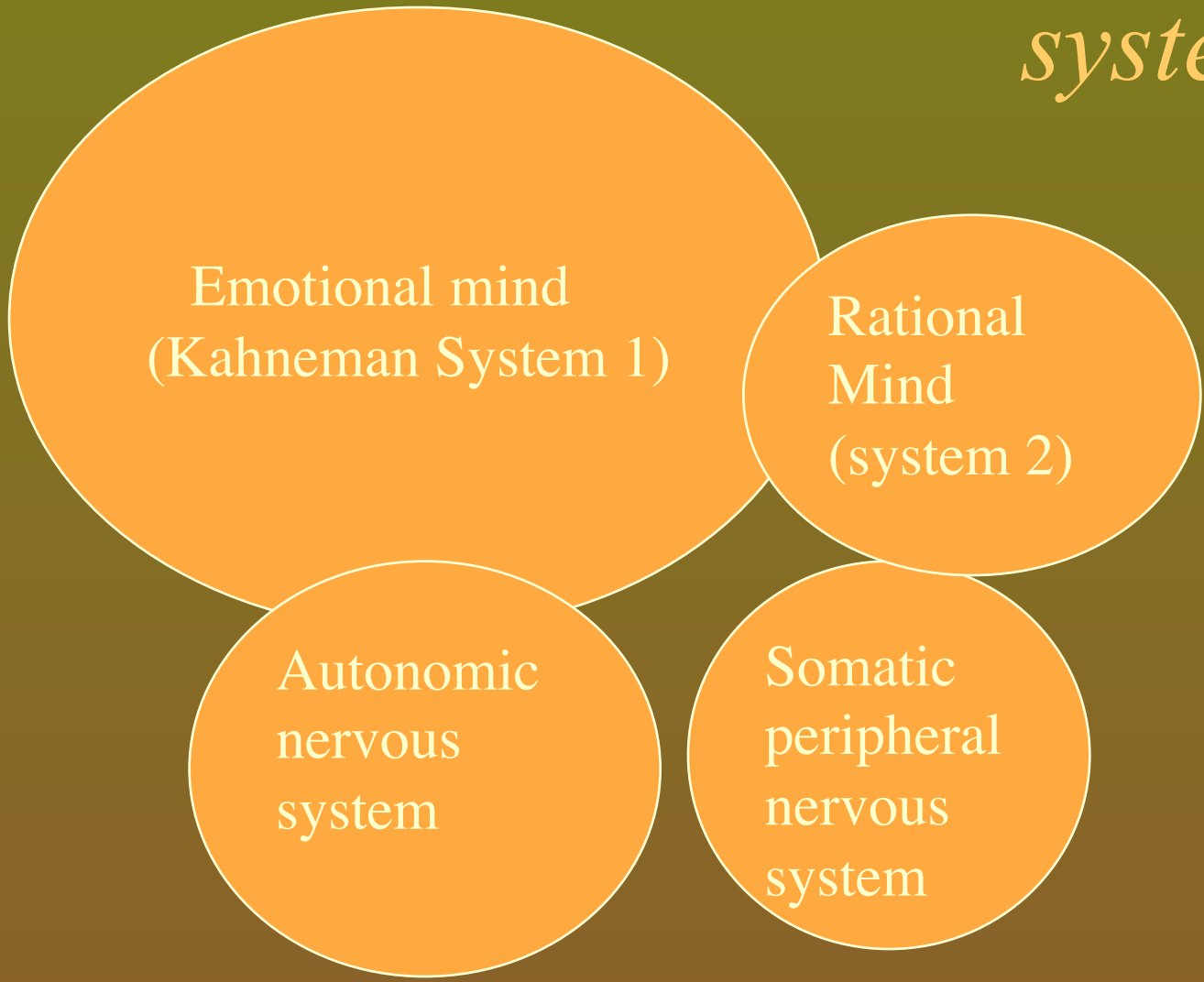
Increasing emotional disconnection

Increasing Trauma (Phobic response)

What are the emotions and why do we have them?

- Not easy to study *via* logical positivist approach
- Anger, disgust, fear, happiness, sadness, surprise, and control of automatic pilot
- Highly evolved; fast
- Important in decision making and planning and control of automated processes including pre-learned motor subroutines.

The organisation of the nervous system



Functional illnesses categorisation

- Dissociative events (phobic response to memory or emotion) - non-epileptic attacks
- Motor conversion symptoms (weakness, slowness, loss of use)
- Disorders of gating of somatic sensation
  - Loss of feeling/sensation
  - Altered or distorted sensation
  - Fatigue
  - Pain
  - Sensitivity to environmental stimuli (e.g. dark glasses)

Non-Epileptic Psychogenic Seizures (NES)

- Types:
  - Dissociative events
  - Behavioral outbursts which are misinterpreted
  - Malingering/manipulative behavior

NES – what the patient experiences

- Little content of seizure description
- Vague
- Unable to say how often they occur
- Associated personality disorder and medically unexplained symptoms

NES - what the eyewitness describes

-Variability in descriptions
-Duration more than 2 mins, often presenting as “status”
-Waxing and waning of motor activity or prolonged unresponsiveness
-Sinusoidal shaking, side to side head movements
-Pelvic thrusting
-Post-ictal crying
-Partial responsiveness during seizures
-Resistance to eye opening
-Unexpected rapid or slow recovery
-May be precipitated by stressful situations

What is dissociation?

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 problem of memory

- The most significant memories are most strongly written in the mind
- Traumatic events are significant, decay very slowly, and precipitate flashbacks
- If flashbacks are intolerable, they become dissociative events
- Dissociation is not unconsciousness in the same way as sleep or anaesthesia – instead it is similar to directed attention or meditation, but an involuntary reflex.

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Non-organic weakness

- Variable loss of function - e.g. a strong hand which cannot grip tightly
- Collapsing weakness
- Weakness with normal tone and reflexes
- Hoover's sign

Non-organic sensory signs

-Whole limb (non-dermatomal) anaesthesia

-Hemisensory loss for all modalities to midline

-Loss of vibration sense on one side of sternum but not the other

-Minor, vague lateralised, brief episodic,altered sensation

-Unimaginable descriptions (“cold burning”)

CFS/ME

- Common, disabling,contentious
- Persistent disabling fatigue in the absence of demonstrable physical cause plus
  - Worse after exercise
  - Sleep disorder
  - Fibromyalgia
  - Intolerance of environmental changes
  - Brain fog

Why do people get chronic FND symptoms?

- Loss of awareness of emotional discomfort caused by stress
  - "But I'm *not* stressed, Doctor!"
  - La Belle Indifference – lack of concern about the seriousness of the disability
- Consider the causes of emotional disconnection…
  - Constitutional, i.e. personality
  - Early deprivation or trauma
    - Early caring responsibilities
    - Living with difficult sibling, family health, disability, substance misuse
    - Peer pressure or competitiveness
    - School issues – bullying, dyslexia

What is going on here?

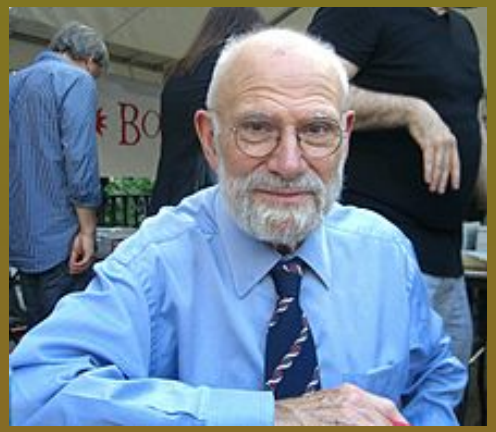
- Precipitated by stressful event, often not perceived as such
- Emotional interference with the filtering (gating) of somatic sensation or disruption of the link between willing and executing movement
- This causes core functional symptoms of:
  - Distortion of somatic sensation
  - Functional movement disorders
  - Fatigue
  - Difficulty concentrating

Why now?

- Symptom onset characteristically *delayed* after stress
- They should therefore be seen as part of the recovery process from chronic severe stress and trauma.

A leg to stand on - Oliver Sacks

- Neurologist at Columbia University, b. 1933, Author of Awakenings, The Man who Mistook his Wife for a Hat
- Wrote about the experience of losing function in his leg four times
  - occurred after being frightened by a bull!
  - ‘an enormous animal sitting on the path..it had a huge horned head, a stupendous white body and an enormous milk white face. In my terror it changed before my eyes, becoming transformed from magnificent to utterly monstrous..the great bulbous eyes became radiant with malignance...the bull became hideous beyond belief, hideous in strength, malevolence and cunning..it seemed now to be stamped with the infernal in every feature. It became first a monster and now the Devil.



A leg to stand on...

- After surgery to his knee
  - "..I tensed the quad - and, inexplicably, nothing happened, nothing at all....I tried again - a strong pull this time - watching the quadriceps closely. Again nothing - no visible motion whatsoever, not the least trace... I had a qualm of absolute horror and shuddered; and then the emotion was immediately repressed or suppressed. I hurriedly shifted my attention to pleasanter things."
- With the physiotherapist
  - "It didn't come, nothing came at all...It was a dead-weight...I saw my own concern and disappointment writ large on [the physiotherapist's] face...I felt the effort diffuse uselessly, unfocussed...I felt that it had no proper point of application or reference. I felt that it wasn't really trying, wasn't really willing...it was precisely that which was missing...I could not think how to contract the quadriceps any more. I couldn't think how to pull the patella and I couldn't think how to flex the hip....feeling I had forgotton something quite obvious, absurdly obvious, only it had somehow slipped my mind."

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A leg to stand on..

- The dysfunction is also sensory - Dr Sacks completely loses kinesthesia:
  - "Dr Sacks..look where your let is - you' ll have the whole thing on the floor....I levered myself up. I had been flat on my back. I looked - and looked harder. The leg was not there! Incredibly, impossibly, the leg was not there. Where was it? I spotted the cylinder of chalk way of to my left, sticking out at a funny angle to my trunk and ... more than half off the bed. I must have kicked it here with my good leg, without knowing, whilst asleep....' Nurse, would you be so kind as to move my leg back?' ...To my surprise she did nothing. Instead she bent over the bed, straightened up and started for the door. 'What' s going on? I' m still waiting, please, for you to move my leg back.' 'Now you're joking, Dr. Sacks. I did move your leg back!' "

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Why did Dr Sacks develop FND?

- At age 8 sent with his older brother Michael to 'a hellhold of a boarding school in the countryside, run by a headmaster who was an obsessive flagellist.'
- "When I was 21 and home from college, I accompanied my father one evening on his rounds. We were driving in the car, and he asked me how things were going. Fine. Did I have any girlfriends? No. Why didn't I have any girlfriends? I guessed I didn't like girls … Silence for a few moments … Does that mean you like boys? Yes, I replied, I am a homosexual.
- "I asked my father not to mention this to my mother under any circumstances: it would break her heart—she'd never understand. The next morning, my mother came tearing down the stairs, shrieking at me, hurling Deuteronomical curses, horrible judgmental accusations. This went on for an hour. "You are an abomination. I wish you had never been born." Then she fell silent. She remained completely silent for three days, after which normalcy returned. The subject was never mentioned again during her lifetime.
- "My analyst tells me he's never encountered anyone less affected by gay liberation. I remain locked in my cell despite the dancing at the prison gates."

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Doctors only willingly diagnose conditions for which they can offer treatment

- Treatment begins with effective communication of the diagnosis
- Mean cost £231; cost per QALY for treating PNES £5,300

Anything else to offer?

- Pacing
- Graded activity programme
- Physiotherapy

Prognosis

- Uncertain, but prevalence decreases with age
  - some patients do well, but difficult for them to see it
- Some get stuck − bad prognosis:
  - Receipt of benefits
  - Unprocessed trauma
  - Unable to accept biopsychosocial model of illnes

Malingering and Munchausen syndrome

- Malingering – fabrication of symptoms for gain
- Munchausen – severe form in which people will make themselves ill
- Munchausen by proxy

Conclusions

- Functional symptoms are stereotyped and can easily be understood as disorders of emotion processing
- Predisposing factors for these can be understood using a simple model of the way people adapt to emotional stresses
- Optimising management is a major challenge for clinical staff.

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