

# Epilepsy, Stigma and Quality of Life

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# Outline

- Biological, psychological and social mechanisms in 'open systems'
- Interactions between mechanisms
- Biological 'matters', psychological 'conditions', and social 'contextualizes'
- Focus on the social, and on stigma
- 'Hidden distress model of epilepsy'
- Countering the 'epilepsy *habitus*'
- Ideas for a research programme

# Structures, mechanisms, powers and tendencies

The objects of natural and social scientific enquiry have causal *powers* by virtue of their *structures*. In this respect they function as *mechanisms*. Mechanisms cause things to happen in the world but are only operative when triggered. What are conventionally defined as causal laws are thus best seen as *tendencies*.

# Interactions between mechanisms

Mechanisms can travel 'upstream' (from the biological to the psychological and/or social)

Mechanisms can travel 'downstream' (from the social to the psychological and/or biological)

# What is epilepsy?

A tendency to recurring generalized and/or partial seizures with varying underlying pathologies (which may or may not be identified by available technologies)

# Examples of complexity

1. Inherited thresholds
2. Sub-clinical epilepsy
3. Non- or misdiagnosis
4. Clinical iatrogenesis
5. Temporal lobe epilepsy

# Back to the biological, psychological and social

Of salience to objective and subjective  
dimensions of quality of life:

- Biology *matters* but is rarely decisive (+  
upstream – eg cognitive deficit)
- Psychology *conditions* via personality (+  
upstream – eg coping style)
- Social *contextualizes* (and allows for  
evaluation)

# Not forgetting trips downstream

The social, for example, frames, and therefore shapes, not only the psychological (*gaze*) but the biological (*gaze*)

# Focusing on the social - 1

‘Hidden distress model’:

1. People develop ‘special view of the world’ which is predispositional and features *felt stigma*;
2. First-choice strategy of concealment minimizes risks from *enacted stigma*;
3. Felt stigma more disruptive of personal lives than enacted stigma.

# Focusing on the social - 2

**Enacted stigma:**  
discrimination because  
'imperfect being'

**Enacted deviance:**  
discrimination because  
of 'immoral behaviour'

**Felt stigma:** sense of  
shame/internalized fear  
of enacted stigma

**Felt deviance:** sense of  
blame/internalized fear  
of enacted deviance

**Project stigma:** strategy  
to avoid/combat enacted  
stigma without falling  
prey to felt stigma

**Project deviance:**  
strategy to avoid/combat  
enacted deviance  
without falling prey to felt  
deviance

# Focusing on the social - 3

Stebbins' 'special view of the world' might be elaborated, following Bourdieu, in terms of an *epilepsy habitus*

Felt stigma is only one aspect of the *epilepsy habitus*, others including bodily and extra-stigma constraints and impediments to projects

# Research programme

Empirical exploration of:

1. *Epilepsy habitus*
2. Contexts of activation
3. Contexts of non-activation
4. Circumscription of contingency
5. Critical junctures/intervention opportunities