

# Running out of time: the experience of living with a neurological condition

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## Structure of the paper

- Background to phenomenological sociology and disability studies
- Dive into the rich empirical material to foreground the voices of the families met
- Experience of Diagnosis
  - Including the period of waiting and testing
- Conclusion

- 2010-2013 funded by MND Scotland to explore the experiences of those who are diagnosed with MND and their families in Scotland (Ferrie, Robertson-Rieck & Watson, 2013)
- to document their perceptions of the diagnostic procedure, of living with MND, of services and service providers, and of their social relationships with family, peers and professionals.
- to develop appropriate methodological approaches and methods for researching the experiences of people with MND.
- Follow-up studies in 2017 (examining Speak Unique for the Chief Scientists Office with Philippa Rewaj; and clinical and genetic data management project for MND Scotland with the Euan MacDonald Centre

## Background: Motor Neurone Disease

- MND, is a terminal neurodegenerative disease
  - affecting about 1 in 50,000 people and there are roughly 3,000 people in the UK with the condition.
- No known aetiology
- First symptoms arise either in the limbs (spinal onset) or speech and swallowing (bulbar onset)
- The cause of death is usually respiratory failure within 18 months of diagnosis.
- "progressive imprisonment without parole" (Tony Judt 2010)
- Over 92 interviews and 5 focus groups conducted over 18 months 2011/2013
- Involving 40 families, most interviewed 2-4 times
- Plus an additional 20 interviews conducted in 2017/2018

# Disability Studies & phenomenological sociology

- Underpinned by the social model, disability studies scholars look for structural barriers to being and doing, that exist for disabled people, or at the intersection of impairment and other 'protected characteristics' (age, gender, sexual-orientation, religious expression and so on), and aim to remove them
- So there's a layer of activism within this scholarly approach
- In turn, from Marx, sociologists are supposed to be useful.
- The phenomenological sociology approach (e.g. Allen-Collinson & Pavey, 2013) is particularly useful as it examines the body as a site for understanding socially-produced barriers

# The sociological body

- Embodiment, along with inter-subjectivity, temporality and spatiality is a central analytical pillar within the phenomenological research approach
- *Lieb* – the focus on the body, as it delivers experience, a subjective link between mind and body and world. This is understood as a dynamic relationship, and stands in contrast to:
- *Körper* – the body is an object, a medical model perspective
- Not to suggest that clinicians only see *Körper*, but in the short time they see patients, and given their role in diagnosing, treating, giving a prognosis, *Körper* traditionally dominates in the UK health system.

- This paper also uses two concepts from medical sociology
- Bury's (1982) concept of biographical disruption, conceptualises the diagnosis of a chronic condition as an end point, of one reality ending, though, with effort and time individuals are able to 'biographically repair'
- Taking this concept to the experience of MND, considered not chronic, but 'unstable terminality' (Lerum et al, 2015), Locock et al (2009) found from their qualitative interviews evidence of biographical abruption, in their words the diagnosis was 'a life-sentence'. Little evidence of biographical repair

- Our interviews took a very similar structure to Locock et al's.
- Their participants were also from the UK, and though English, the healthcare structures as they relate to neurological services, are very similar in Scotland and England.
- We also had roughly similar sample sizes.
- In the interviews we completed, participants were shocked by their diagnosis, and their experience was brutal. There was evidence of abruption, but in most cases there was also evidence of biographical repair.
- Our longitudinal approach almost certainly allowed for this finding to emerge.

# Diagnosing MND

- As receiving a diagnosis of MND is brutal, so giving it, is brutal.
- Christakis (1999) argued that medical professionals can delay diagnosis, and avoid giving a clear prognosis, particularly when the prognosis is bad and short-lived.
- The diagnosis is required to allow legitimation to the family
- And to access key services including occupational therapy, home adaptations, specialist equipment, social welfare and physiotherapy
- There is a clear detrimental consequence on families who wait for their diagnosis.
- While medical professionals may feel that '**waiting**' is '**hopeful**', most participants found that hoped turned to fear and frustration as their condition progressed (Ferrie & Wiseman, 2016)
- Thus in this pre-diagnosis stage, avoidance of the *Körper* or *corporeality* (Ferrie & Watson, 2015) is a disruption to the Lieb – to the dynamic interplay between the body and world required for biographical repair to begin

The illness narrative is:

‘... a story the patient tells ... to give coherence to the distinctive events re long-term course of suffering. The plot lines, core metaphors and rhetorical devices that structure the illness narrative are drawn from cultural and personal models for arranging experiences in meaningful ways’ Kleinman (1988:49)

So, if a person with MND has not been diagnosed, or given a clear prognosis, and they are waiting in excess of 6 months for (often unexplained) tests to be completed

And with no narrative from medical professionals to explain the wait, or ‘the pause’

No narrative that they can then adopt and adapt into an illness narrative



- From the initial visit to their GP:
- 27% were diagnosed within 6 months
- 27% within 6-12 months
- 27% within 12-18 months
- And 19% were diagnosed over 18 months later
  
- UK System
- Families register with a GP, in rural areas, this is likely to be a named GP who will see families regularly (not always frequently), in urban areas, though the family also has a named GP they are unlikely to meet this GP, instead, who they see is determined by when the appointment is made
- Once a GP is convinced the symptoms is serious, they tend to get referred to either a stroke consultant (most common with bulbar presentation) or a neurological consultant. Stroke consultants tend to be available more quickly, but don't always help refer patients on to neurological services. A wait to see a neurologist can take over 6 months.

# Convincing the GP

- Was tough.
- [GP] asked me what my symptoms were and I showed him my hand and I told him about my leg and he just said ‘Just a coincidence’ ... and I was angry with him
  - Patsy
- [the GP said] ‘right, going to press down on your things and I want you to push back as hard as you can with both legs’ and ... and he said ‘Matthew, you’re as strong as an ox’ and looking back on it, it was because we’d retired and I thought it didn’t seem right but however, we accepted it.
  - Nicola, speaking with husband Matthew

## Waiting to see a neurologist

- But we had to push and push to get appointments and to get diagnosed because it was just waiting a couple of months and waiting a couple of months and it was too much of a worry ... So, we just kept phoning up their secretaries and everything. Just push push push to get the test.
  - Charlotte speaking with husband Tom
- So I came off the phone (to GP) and I thought ‘My God, if I have to wait another 5 or 6 months, I don’t think I’ll be able to walk by that time’. My family and my daughter and that, they are cracking up, so I thought about it and I thought ‘see to tell you the truth, I don’t think that I could wait six months. I’m starting to get a bit panicky now.’
  - Marie

## Distress giving a diagnosis

- Participants expressed empathy and sympathy for their doctors  
Jean: ... and then we went to the doctor that afternoon and the GP was just shocked

Alex: He looked absolutely shattered

- Sympathy for the doctor was given, even where it seemed evident that the diagnosis was known, but delayed. Mike was given a diagnosis of MND in a morning appointment. His wife was with him at the hospital but not invited into the clinic. Mike was unable to tell his wife:

Claire had got herself in a state worrying about me so she phoned [consultant] back. So, [the Consultant] got quite upset to be fair to him, he said, 'tell Mike not to worry, it probably isn't motor neurone, in fact I am 90% sure that it is a trapped nerve.

- The same consultant finally gave the diagnosis of MND 6 months later.



## Hostile environment for biographical repair

Both quotes from Patsy, a former nurse:

I said to [diagnosing consultant] 'what happens now?' and he said 'what do you mean?' And I said, 'Well, do I have more tests or do I come back?' he said 'do you want to come back?' and he said I could take the Riluzole, and he said 'It can cause liver damage' ... he was so removed and I really felt as though he might as well have said (and I certainly felt it) 'well, you're finished. Off you go ...'

And later:

I still feel that the medical profession sees me as just a diagnosis. That is not to say that they are unkind, but that is their end of the spectrum. em .... The .... Well, they don't know me as such ... [becoming upset]

Jo: So it's hurtful? Each time you encounter it?

[sobbing] I ... I try to be free of it mentally, but you feel as though you're pulled back

# Not helped by some medical professionals

- Giving and receiving a diagnosis of MND must be brutal but some seemed to avoid sensitivity
- I started to ask a few questions because ... I am like that .... Question, question, question .... And he answered I think, two questions and then he said ‘well you know, I have got other patients to see and I fully understand that and I fully appreciate that but we walked out that door just having been told that Philip was dying
  - Kate, with her husband Philip
- Simon: I had the EMG and that was absolutely clean ... the guy who gave it to me said ‘The test is clear but in my opinion, you have Motor Neurone Disease and you will ...

Penny: ‘your body will succumb ....’

Simon: You will succumb to the disease within five years ...’

Jo: Oh ...!

Simon: ‘and pick up some leaflets on the thing on the way out!’

Jo: Oh ...!

- This approach effectively cut-off an early opportunity to talk through ‘what next?’, step 1 in biographical repair.
- The experiences in the most recent interviews were as concerning. And yet there were some good stories, of participants being given time and a quiet room:
- He sat with us for a bit and did say to us that there is support out there for you
  - Paula, talking with her husband Alan



- Here clearly Patsy and others have been reduced to *Körper*.
- While participants are able to acknowledge that this is the essential point of medical professionals, still the prolonged absence of an illness narrative during diagnosis
- And the difficulty of giving a diagnosis
- Meant that the body, as understood through Lieb, had been absent
- While waiting for a diagnosis, participants had allowed their changing body and functioning, to be bracketed as a medical phenomenon, rather as central and informing of their existence
- The shock of diagnosis, combined to produce an abruptio<sub>8</sub>

- Unable to share the data due to time constraints, but we have narratives that show, an earlier diagnosis shows quicker biographical repair
- That biographical repair was available to most participants **over time**
- Therefore shorter diagnostic periods are advantageous for existential recovery
- In addition: provision of medical services in a way that allows professionals to recognize the *lieb* as well as the *körper* will help participants accept and adapt to their changing world, as well as their changing body – rural GPs most able to provide this narrative
- Clearly giving a diagnosis is traumatic, and more psycho-emotional support should be available to Consultants.