



# Understanding the Lived Experience of Cerebellar Ataxia

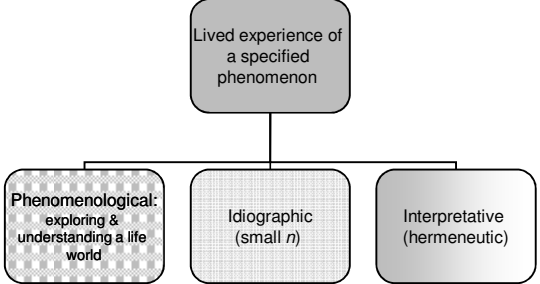
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## Aim

- Introduce Interpretative Phenomenological Analysis
- Briefly discuss how IPA might inform practice
- Present interim findings
- Discuss the possible implications for physiotherapy

## What is Interpretative Phenomenological Analysis?



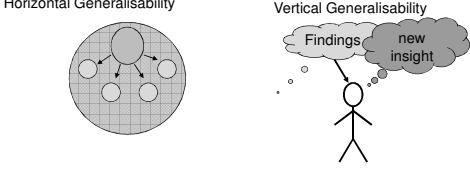
Lived experience of a specified phenomenon

Phenomenological: exploring & understanding a life world

Idiographic (small n)

Interpretative (hermeneutic)

## How Can IPA Inform Practice?



Horizontal Generalisability

Vertical Generalisability

- Generalisability is multidimensional (Johnson, 1997)
- Horizontal generalisability: across settings and samples within the original population (nomothetic)
- Vertical generalisability: provoke a reappraisal of what is known (idiographic), theoretical generalisability

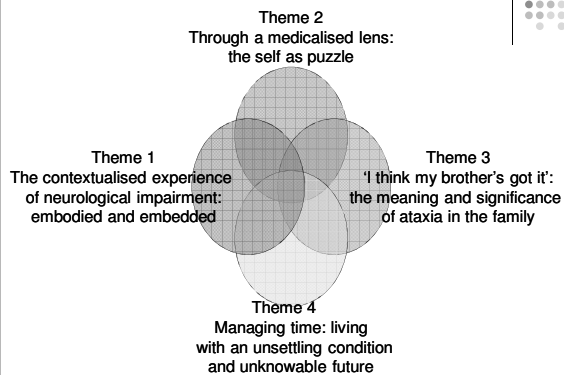
## IPA in Action

- No qualitative research about the experience of living with ataxia
- Recruitment via Ataxia UK
- Semi structured interviews
- Open questions
  - Can you tell me what living with ataxia is like?
  - Can you describe in more detail how ataxia has affected your day to day activities, the things that are important to you?

## Participants

- 12 people with cerebellar ataxia
  - 8 men
  - Age range: early 30s –late 60s
  - Ataxia 1- 25 years
  - Median: 13 years
  - 1 full time wheelchair user
  - 5 in work
  - 7 retired
  - Experience of Physiotherapy ✓

## Overview of Interim Findings



## Exploring Theme 1

The contextualised experience of neurological impairment: *embodied* and embedded

### Commonly Reported Impairments

Imbalance and falls (n = 12)	Fatigue (n = 11)
Incoordination (n = 9)	Speech problems (n = 9)
Fluctuating symptoms (n = 9)	Visual problems (n = 7)
Cognitive processing (n = 8)	Aches and pains (n = 5)
Tremor (n = 5)	Incontinence (n = 3)

## Exploring Theme 1: Describing the Indescribable

*'It's like everything is uncoordinated. The frustration of a thing making perfect sense when you say it in your head, but by the time it emerges from your mouth it's kind of clumsy and awkward and ... the same with moving about. It's awkward, ungainly and painful and you can't do things quickly or arrogantly or whatever. Everything's kind of thick, knobbly and ungainly, uncoordinated, clumsy and just ... it's almost like being drunk all the time, except you aren't.'* Bill

## Exploring Theme 1

'It's like being drunk all the time with no cause for being drunk'  
'my head was a fishbowl' 'knees were like jelly' 'legs like lead'  
'wide at the top like a pivot' 'like a tin soldier'  
'thick, knobbly, ungainly' 'like a matchstick man'  
'like a pin ball' 'awkward, ungainly, painful' 'rusty'  
'my head was a fishbowl' 'I don't flow as normal people do'

- Subtheme 1: *'My head was a fishbowl'*
- Describing the indescribable – an unfamiliar self

## Exploring Theme 1

Embodied and *Embedded*

*'And I could not ... particularly if people were behind me, walking behind me, that tends to make me worse ... but I was like a pinball, I was bounced off this wall, went to that wall, I could not walk in a straight line down that corridor [...] Really strange.'* Toby

## Exploring Theme 1

Embodied and Embedded

- *'I don't like to go in the social situation where I feel I'm being judged'* Susan
- *'If I think people are watching me I just freeze and my legs won't work'* Stella
- *'I don't want to seem odd in public'* Julia
- *'Loads of pairs of eyes going chu-chu-chu – looking at you and thinking what's wrong with him?'* Jim

## Exploring Theme 1

### Embodied and Embedded

*'I should use a walking stick, I've got one in my bag, but I'm still coming to terms myself with the fact that I need to use it, being seen to be using it ... which is more about my own preconceptions and image I suppose. [...] but having something so obvious as a walking stick, it's just a visible sign to everybody – yes I am definitely different.'* Jim

## The contextualised experience of neurological impairment: embodied and embedded

- Subtheme 1: *'My head was a fishbowl'* (Julia)  
Describing the indescribable – an unfamiliar self
- Subtheme 2: *'I don't want to seem handicapped in any way'* (Stella)  
Ataxia as an embodied experience played out in public

## Discussion

- Richly detailed data about the personal experience of living with ataxia
- Shame and stigma associated with 'disordered walking' seemed to form a significant part of the experience of living with ataxia
- The experience of stigma is bound up with the work of physiotherapy (Sim 1990)
- Physiotherapists are well placed to listen to and appreciate the personal significance of patients' narratives and their complexities and to offer practical support

## Acknowledgements

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- Ataxia UK for funding the initial study – the study report can be found at: <http://www.ataxia.org.uk>  
'Contemporary physiotherapy practice for people with ataxia: the perspectives of clients and physiotherapists'.
- Register with Ataxia UK as a healthcare professional to receive information about the physiotherapy for people with ataxia guidance document.

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## References: Examples of IPA

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