

The end of life in PD and the Parkinson's plus syndromes: a mixed methods study

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Background:

- ▶ Why end of life?
- ▶ What do we know already?
 - ▶ Significant burden of symptoms - palliative care need
 - ▶ Lack of co-ordination of services and carer support pre/post death in PD
 - ▶ Place of death for PD
- ▶ What do we want to know?
 - ▶ Does place of death make a difference to the end of life experience?
 - ▶ What are the important issues at the end of life?
 - ▶ Have people made advanced plans/thought about the future?
- ▶ Why do we want to know?
 - ▶ Can we improve the delivery of end of life care for these groups?

Additional important considerations

- ▶ Study participants
 - ▶ bereaved carers
- ▶ What does end of life mean?
- ▶ Is the end of life different for Parkinson's plus vs PD?
- ▶ What factors might we consider make a 'good death'?
- ▶ Place/environment
 - ▶ Conflicting social science literature
- ▶ Acceptance
- ▶ Loved ones near/spirituality

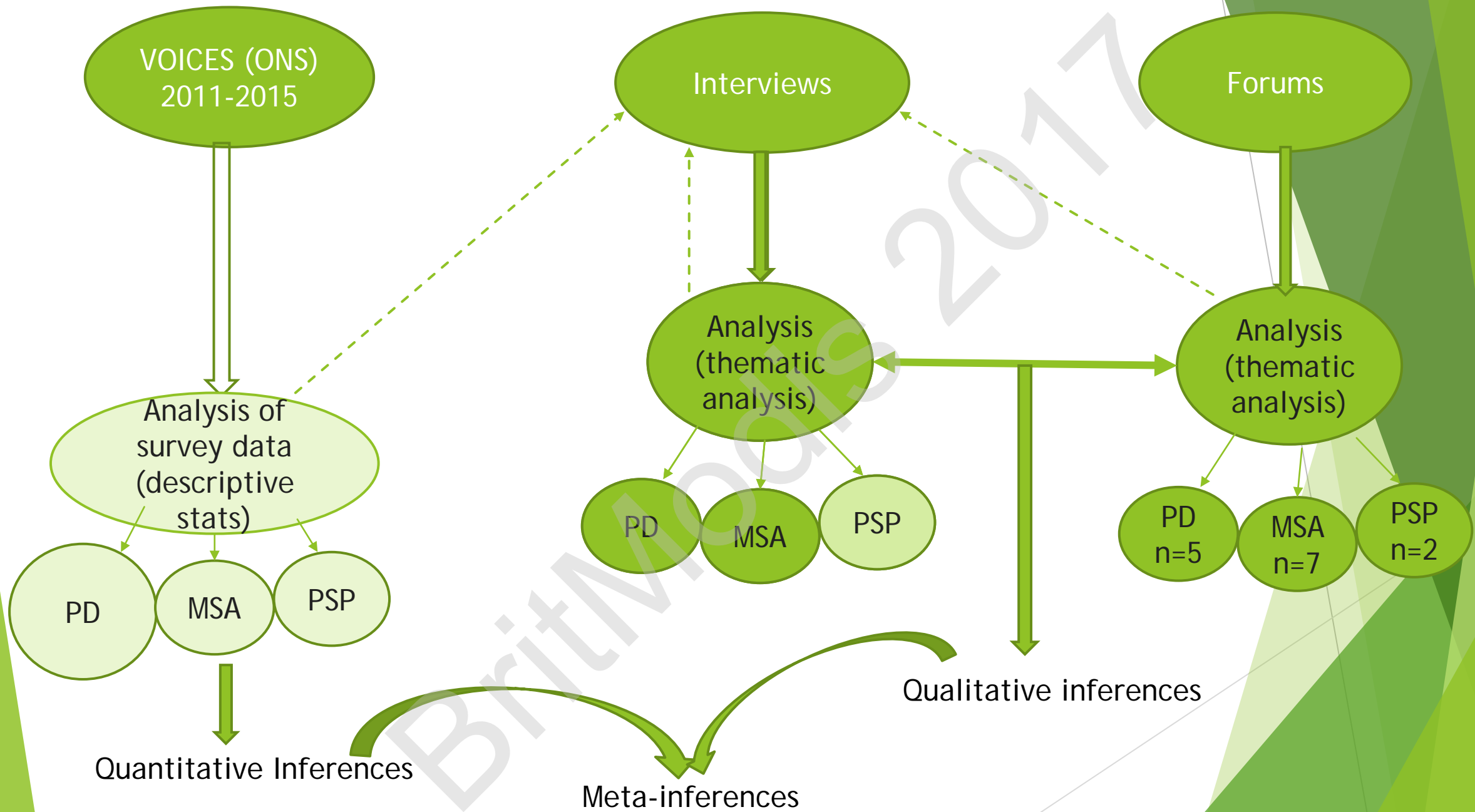
Mixed methods rationale

- ▶ Not a lot of info out there so largely wanted an exploratory study (QUAL)
- ▶ Place of death +/- advanced decisions captured well in existing surveys of bereaved carers (QUAN)
 - ▶ VOICES (Views of Informal Carers - Evaluation of Services)
 - ▶ ONS: National survey of bereaved people 2011-2015
 - ▶ ECHO-D (Experience of care and health outcomes - for the dying)
 - ▶ CODE (Care of the Dying Evaluation)
 - ▶ RCP: National care of the dying audit of hospitals

The project

- ▶ Mixed methods approach
 - ▶ Quantitative
 - ▶ VOICES
 - ▶ Qualitative
 - ▶ Internet forums
 - ▶ Semi-structured interviews
 - ▶ Local and national
- ▶ Parallel concurrent design

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MSA initial coding/analysis: identity

- ▶ Mistaken identity/ignorance
 - ▶ “The ward doctor changed all of her meds, and when I questioned why said ‘well it’s Parkinson’s isn’t it?’ so I think these drugs would be better (MSAitel03)
 - ▶ Death certificates
 - ▶ ‘I made sure MSA was on there’ (MSAitel04);
 - ▶ I’ve put pneumonia I said, ‘you’re not, you’re putting MSA’ (MSAitel03);
 - ▶ ‘I did notice they’d spelt it incorrectly ... respect’ (MSAitel06)
- ▶ Advocacy and the fight
 - ▶ Battle, co-ordinating carers/PT etc
 - ▶ Expert carers
 - ▶ “I carried leaflets about the disease everywhere I went”
 - ▶ “a different district nurse would come out and I’d have to explain everything again and I said ‘there’s no continuity’” MSAi02; the need to ‘educate’ locum GPs every time a home visit needed`MSAf03
- ▶ Brain donation

MSA: Ignored/isolated

- ▶ Isolating

- ▶ 'Still there'

- ▶ " and I think that's another thing um when the nurses came out they would ask me but with multi system atrophy the person's still there... they're locked in this body that's let them down. It's not like alzheimers, the dementia, coz the person's still there and that's what I tried to tell them" MSAi02
 - ▶ "he was still there in the head you know, they'd go 'oh I bet he don't know nothing about it' well actually he's more acute than what we are [laughs] um you're living in a prison in your own mind" MSAitel01

Impact on patient

▶ Euthanasia

- ▶ 'he made a gun with fingers to his head' 'he said I may as well drive off the bridge' MSAi02
- ▶ Family watching TV documentary on lady going to Switzerland (dignitas) and person with MSA (dad) says "'have a look, see how much it is', I went 'ay' he said 'you'd do it wouldn't you' I said 'I don't know' MSAitel01
- ▶ 'P had discussed with me many time the option of euthanasia, in the last stages she would've taken that option, indeed asking me to help her, which was something I could not directly do' MSAf03
- ▶ But... Also uncertainty about when it would be done - meaning when person/carers view themselves as dying

Impact on carers

- ▶ Death often unexpected by carers even though they knew illness was palliative
- ▶ Impact on carers
 - ▶ Not really understood by healthcare professionals
 - ▶ Several had thought about suicide
 - ▶ No official support offered
 - ▶ Compassion and care towards relative helped a lot

PD initial coding

- ▶ Being 'PD aware' important
 - ▶ Medication
 - ▶ What end of life is like/advanced stages are like
- ▶ Withdrawal of services/giving up
 - ▶ When my dad deteriorated and was unable to go and see the consultant no one came to see him. You get the feeling that everyone gives up and you'd just helplessly watching this person deteriorate and no one helps them or their carer PDF04
- ▶ Lack of support, no bereavement support
 - ▶ More support should be offered after death PDF04
 - ▶ I found my own support PDF01

Shared issues - likely with all end of life

- ▶ Often hospitals are disorientating, bewildering, stressful
- ▶ A humane touch is appreciated - care homes do well
 - ▶ De-medicalised
- ▶ Planning for the future is very individual
 - ▶ Information gatherers/avoiders
 - ▶ Plans/ADRTs gave control to person with the disease and guided carers
 - ▶ ?better made earlier
- ▶ Carers' role and impact on them
 - ▶ Lack of support during dying and after death

Differences...

- ▶ PD fight for aspects of care, MSA for knowledge of their existence

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Discussions

- ▶ Can look at MSA and PD as separate entities (and PSP)
 - ▶ If similar themes can analyse across groups
 - ▶ If not, think why
- ▶ Compare at least PD to national VOICES data
 - ▶ additional weight to potential disadvantaged care vs cancer)
- ▶ Do people make advanced decisions and explore why they do/do not
- ▶ ????? More may emerge

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Reflections

- ▶ Being a doctor affects data collection and analysis

- ▶ Assumptions
- ▶ Less frustration for MSA
- ▶ Influence data collection
 - ▶ Sudden death

- ▶ Sobering

- ▶ I thought we did better in hospitals
- ▶ Remember who the experts are!

I: 'with Parkinson's disease you have it for such a long time you know your own body and..'

P: "yeh, well you're the expert aren't you, they may be the professionals but you're the expert"
PDitel01

What would you ask?

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Any other questions?

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