



# Defining the Palliative Care Needs of People with Progressive Neurological Conditions

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- Aims and methods – see flyer, handout
- Recruitment
- Description of problems and symptoms using palliative care assessment- POS. Preliminary data to give flavour
- Comparison to literature review, MS, cancer – see hand out

# Aims

- To **describe** the physical, emotional, social, healthcare and information needs of people living with advanced PD, MSA and PSP
- To identify the key factors associated with impaired **quality of life** (QL), unresolved symptoms and psychological needs in people affected by these disorders
- To identify key factors that influence **health costs**
- To provide evidence of **palliative care needs** and trigger points for referral to palliative care services for these groups

# Methods

**Longitudinal study (3 years):** mixed methods, face to face recorded interviews. Follow up 3 to 4 time points for year

## 1. Quantitative

- 60 people advanced Parkinsonism
- their carers

## 2. Qualitative

- views gathered from pts and carers during Quant interviews (meat on bones), further exploration after cross-sectional analysis to inform topic guide

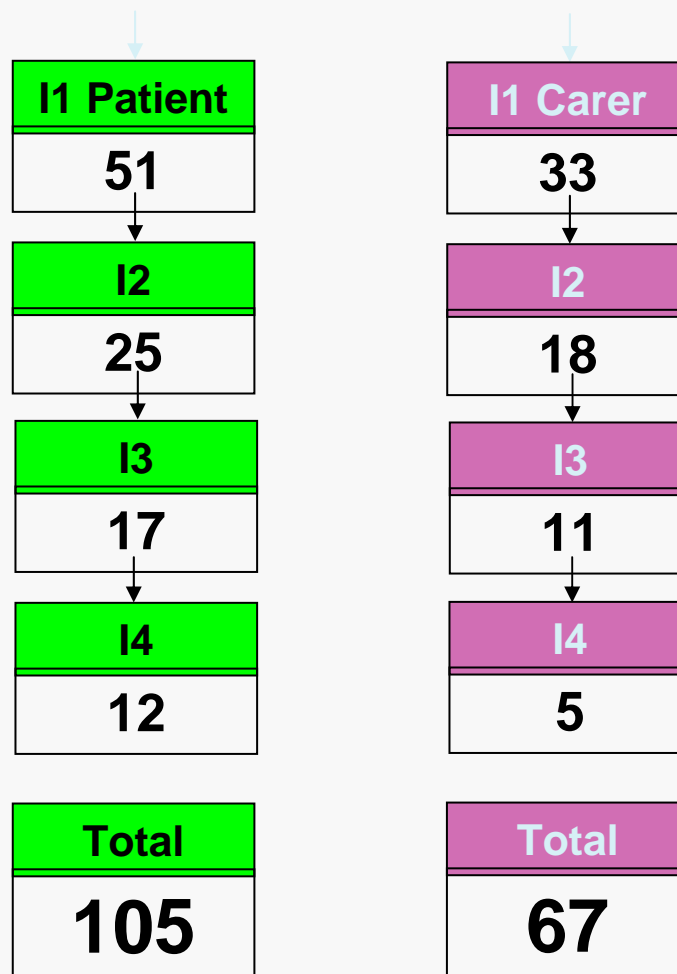
## Data collection phase (month 17)

- **Quantitative** interview comprises:
  - validated and exploratory measures of physical, emotional and cognitive difficulties
  - quality of life
  - palliative care outcomes (today will share preliminary findings-cross sectional baseline data)
  - carer burden
  - health cost
- **Qualitative** interviews will explore experience and views on symptoms, end-of-life care, information and support

# Key tasks in last 6 months

1. Recruitment: patients, carers, follow up interviews
2. Research assistant
3. Data entry on SPSS
4. Preliminary/exploratory analysis - base line cross sectional data- POS

# Follow up interviews: Patient & Carer pairs



## In Study – Parkinsonism: 3 conditions

<b>Condition</b> Parkinsonism	<b>Patient</b>	<b>Carer</b>
1. Parkinson's Disease (PD)	33	19
2. Progressive Supranuclear Palsy (PSP)	11	9
3. Multiple Systems Atrophy (MSA)	7	5
<b>Total</b>	<b>51</b>	<b>33</b>

# Recruitment at Kings College Hospital

- Movement disorder clinic KCH
- Attended by neurology consultants, PD nurse, speech & language, physio, Occupational therapists
- Issues of concern flagged up by some patients in the study are brought to the attention of the relevant consultant or PD nurse specialist in charge of their care

# Recruitment Issues

- Less prevalent conditions PSP & MSA. Were to use cohort from another study- NNIPPS. Due to delay in securing funding and start of this project (June 2007) this pt cohort is in a very advanced disease and most have now died
- Now pursuing another strategy by recruiting via neurology clinics, PSP and MSA associations
- Currently in month 17 of this 36 month study. Pts and their carers are to be followed up at least for 3 occasions over a 12 month period. We plan continue to recruit new pts until month 21 (Feb 09)

## Demographics

- **Male** 57% (n = 26)      **Female** 43% (n = 20)
- **Mean Age** 68      SD = 8
- **Geographical Area** South East London, Kent, Surrey, Sussex. Travel time ( 4 hours return trip max)

# Advanced Disease Staging

Disease Severity  
Hoehn & Yahr (1967)  
**Stages 3,4,5**

**(3)** Mild  
bilateral disease  
  
**20 %** (n = 9)

**(4)** Severe  
disability  
able to walk  
or stand  
  
**37 %** (n=17)

**(5)** Wheelchair  
bedridden  
Unless aided  
  
**43 %** (n = 20)

# Assessment of Palliative Care Needs

- **Palliative Outcome Scale (POS)** Hearn & Higginson
  - 10 item questionnaire: physical, psychological, social, and practical concerns, plus concerns about information
  - item is scored from 0 -4, with increasing scores corresponding to worse problem or concern
- **POS-S-P** symptoms and severity rating
  - 22 item

<b>POS question</b> (0 = none and 4 = severe)	<b>%</b>	<b>Mean</b>	<b>S.D</b>
Affected by other symptoms*	<b>96</b>	<b>2.37</b>	<b>1.06</b>
Affected by pain	<b>89</b>	<b>1.96</b>	<b>0.97</b>
Family anxious or worried	<b>85</b>	<b>1.91</b>	<b>1.19</b>
Not felt good about self	<b>91</b>	<b>1.91</b>	<b>1.15</b>
Not able to share feelings	<b>66</b>	<b>1.46</b>	<b>1.44</b>
Anxious or worried	<b>67</b>	<b>1.30</b>	<b>1.15</b>
Feeling depressed	<b>57</b>	<b>1.11</b>	<b>1.20</b>
Practical problems	<b>59</b>	<b>0.98</b>	<b>1.27</b>
Level of information poor	<b>72</b>	<b>0.71</b>	<b>1.06</b>
Time wasted on appointments	<b>24</b>	<b>0.63</b>	<b>1.18</b>
<b>Total POS Score</b>		<b>14.24</b>	<b>5.24</b>

# POS-P

6 symptoms reported in more than 80 % ● of patients

Symptom	% (n=46)
Feeling sleepy	89 ●
Problems using legs & walking	87 ●
Pain	87 ●
Fatigue or lack of energy	87 ●
Mouth problems (Dribbling)	80 ●
Problems using arms & hands, writing	80 ●

# POS-P

6 symptoms reported in more than 50 % ●

Symptom	% (n=46)
Difficulty communicating (speech)	72 ●
Spasm/Stiffness	65 ●
Difficulty controlling urine	63 ●
Difficulty sleeping	59 ●
Constipation	57 ●
Shortness of breath	50 ●

# POS-P

8 symptoms in under 50 % ●

Symptom	% (n=46)
Problems swallowing	48 ●
Falling	48 ●
Difficulty with bowel control	35 ●
Hallucinations	30 ●
Nausea	26 ●
Poor appetite	13 ●
Vomiting	7 ●
Pressure sores	4 ●

**Literature Review** Saleem T, Higginson IJ, Leigh PN (2008).  
Symptom Prevalence Among People Affected by advanced and Progressive  
Neurological Conditions- a Systematic Review. *Journal of Palliative Care* 23, 291-299

To determine:

- Types of symptoms, their prevalence in progressive neurological conditions
- To what extent these conditions have similar symptoms and problems

Findings:

- Patients with progressive neurological disease **share more than 9 symptoms** in common

Recommendations:

- **Palliative care approaches** from cancer settings may have value for patients with neurological conditions

**Review & current study  $\geq 80\%$  ●,  $\geq 50\%$  ●,  $\leq 50\%$  ●**

Symptom	Current	PD	MSA	PSP
Mobility	●	●	●	●
Communication	●	●	●	●
Spasm/Stiffness	●	●	●	●
Swallowing	●	●	●	●
Bladder	●	●	●	●
Bowel/Constipation	●	●	●	●
Pain	●	●	●	
Fatigue/tiredness	●	●		
Respiratory/breathless	●	●		●
Sleep/Insomnia	●	●		

# Comparison with other advanced diseases

Symptom	P <sup>1</sup>	MS <sup>2</sup>	Cancer <sup>3</sup>
Pain	87% ●	68% ●	35-96% ●
Fatigue	87% ●	80% ●	32-90% ●
Nausea	26% ●	26% ●	6-68% ●
Constipation	57% ●	47% ●	23-65% ●
Breathlessness	50% ●	26% ●	10-70% ●

<sup>1</sup>King's Parkinsonism study - % with symptom

<sup>2</sup>Higginson et al. Journal of Palliative Care, 2006: 158-165

<sup>3</sup>Solano, Gomes, Higginson. Journal of Pain and Symptom Management, 2006: 31:58-69.

## Key tasks for next 6 months

1. Recruit pts, carers and follow up
2. Continue data entry - SPSS
3. Conduct preliminary/exploratory analysis for base line cross sectional data
4. Patients Advisory Group (user group) meeting, Scientific board
5. Develop topic guide for qualitative interviews from base line data
6. Start qualitative interviews, transcribe

# Contact details

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