End stage disease in Parkinson’s

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Typical case

- Man aged 78 - PD for 16 years with recent cognitive decline
- Recurrent admissions – falls, chest infections, urinary tract infections with associated hallucinations and increased confusion
- Now admitted unable to swallow – NG tube
- Discussions with family about artificial feeding (PEG tube) and where patient should be cared for
- What would the patient have wanted?
Content

- Natural history of Parkinson’s disease (PD)
- Prevalence of palliative care symptoms in PD
- Can we predict death?
- Where do patients die?
- What do they die from?
- What about Advance Care Planning (ACP) in PD?
During the presymptomatic phase of Parkinson's disease there is gradual loss of dopaminergic neurons in the substantia nigra until a critical threshold is reached, at which time motor symptoms first appear. The motor symptoms then progress and become associated with other signs of Parkinson's disease.
Natural history in IPD

I : unilateral disease with minimal functional impairment (1-3 years)

II : bilateral or midline involvement without balance impairment (6 years)

III : Postural instability- some restriction in activity but independent (7 years)

IV : severely disabled disease; patient is markedly incapacitated (9 years)

V : restricted to bed or wheelchair (14 years)
Time course of the disease
- MacMahon et al 2004/05

diagnosis        maintenance          complex                   palliative

R Walker - BGS Autumn 2013
Symptoms
Most common symptoms

- Slowness of movement: 109 (88.6%)
- Pain: 104 (85%)
- Tremor: 91 (74%)
- Drooling: 80 (65%)
- Anxiety: 76 (61.8%)
- Drowsiness: 75 (61%)
- Stiffness: 75 (61%)
- Immobility: 72 (58.5%)
- Dry mouth: 66 (53.7%)
- Memory problems: 63 (51.2%)

Lee MA et al Parkinsonism and Related Disorders 2007
‘Palliative care type’
symptoms

<table>
<thead>
<tr>
<th>Symptoms (Cancer) Ellershaw et al</th>
<th>Frequency Ellershaw et al (n = 125)</th>
<th>Frequency NTGH study (n = 123)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>74%</td>
<td>85%</td>
</tr>
<tr>
<td>Immobility</td>
<td>66%</td>
<td>58.5%</td>
</tr>
<tr>
<td>Anorexia</td>
<td>~50%</td>
<td>13%</td>
</tr>
<tr>
<td>Insomnia</td>
<td>~40%</td>
<td>49.6%</td>
</tr>
<tr>
<td>Constipation</td>
<td>~30%</td>
<td>23.6%</td>
</tr>
<tr>
<td>Nausea</td>
<td>~26%</td>
<td>9.8%</td>
</tr>
<tr>
<td>Dyspnoea/ SOBOE</td>
<td>~20%</td>
<td>35.8%</td>
</tr>
<tr>
<td>Vomiting</td>
<td>~15%</td>
<td>4.1%</td>
</tr>
</tbody>
</table>

Lee MA et al Parkinsonism and Related Disorders 2007
Pain prevalence studies

- 15 studies (5 with controls) report prevalence between 25% and 85%
- Variable definitions of pain, e.g., acute versus chronic
- Several classifications for nociceptive and neuropathic pain
Pain in PD in North Tyneside

- Overall pain in PD is present in 85%
- PD pains were found in 62.6%
- Non PD pains were found in 64.2%
- Most PD pain is intermittent
- Non PD pain is generally more severe
- Pain does not get worse with disease progression
- Analgesic use suggests that pain is under treated

Pain key messages

- Pain is common in PD and may not be volunteered by patient
- Identify cause of pain to guide treatment
- If related to wearing off adjustment of PD treatment may help
- Physiotherapy – early, prevention
- Simple analgesics
- Opioids – constipation already a problem in PD, can cause night terrors
Other problems in end stage disease

- Swallowing issues
- Breathlessness – aspiration pneumonia
- Communication issues
  - Cognitive impairment
  - Speech problems
  - Advance Care Planning (ACP)
- Complex symptoms
- Reducing therapeutic options
How do we identify those who are dying?
IPD

The presence of 2 or more of the criteria should trigger inclusion on the PC register

- Drug treatment is no longer effective/ an increasingly complex range of drug treatments
- Reduced independence, need for help with daily living
- Recognition that the disease has become less controlled with less predictable “off” periods
- Dyskinesias, mobility problems and falls
- Swallowing problems
- Psychiatric signs (depression, anxiety, hallucinations, psychosis)
Prognosis in IPD


- Related to respiratory infections

- Life expectancy [Ishihara JNNP 2007]
  - 25-39 years at onset = 38yrs vs 49yrs (control)
  - 40-64 years at onset = 21yrs vs 31yrs
  - >65 years at onset = 5yrs vs 9yrs

- Prognostic factors for progression [Post B et al Mov Dis 2007]
  - Higher age of onset
  - Higher postural instability and gait disorder
Predictors of mortality

- Based on falls cohort recruited at NTGH in 2000
- Abnormal autonomic function tests do not predict mortality
- The results of physiotherapy assessment including mobility and balance do predict mortality

Weight loss as a predictor of mortality – methods

- Patients with PD under the North Tyneside PD service
- Died between 1/1/08 and 31/12/10
- Retrospective review of weight comparing baseline (around time of diagnosis) to weight in years preceding death
- Analysed with 5% weight loss, and 10% weight loss, cut offs

Results

- 77 people met inclusion criteria of whom 55 (71.4%) had reliable weight loss data.
- Mean age at diagnosis was 72.9 for males and 73.8 for females.
- Mean age at death was 79.7 for males and 83 for females.
- Females had higher rates of clinically important weight loss.
- One year survival from time of 5% weight loss – 18/20 (90%) females and 5/18 (27.8%) males.
- One year survival from time of 10% weight loss – 12/16 (75%) for females and 3/13 (23%) males.
- **Weight loss in males highly predictive of mortality.**
Where, and of what, do patients die?
Methods

- Data requested from the Office of National Statistics (ONS)
  - place of death and cause of death (obtained from death certification)
- ONS provided details of data entered on death certificates and the Underlying cause of death as produced by the coding system
- Data provided prior to 2001 was classified using ICD 9, subsequent data is classified using ICD 10
- 227 patients registered on the North Tyneside Parkinson’s Disease Database
  - 143 - Idiopathic Parkinson’s Disease (IPD)

## Cause of Death Compared to Literature

<table>
<thead>
<tr>
<th>Authors</th>
<th>IHD</th>
<th>Cerebrovascular</th>
<th>Malignancy</th>
<th>Pneumonia</th>
<th>PD</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>PD</td>
<td>Control</td>
<td>PD</td>
<td>Control</td>
<td>PD</td>
</tr>
<tr>
<td>Ben-Schlomo et al</td>
<td>23%</td>
<td>26%</td>
<td>17%</td>
<td>14%</td>
<td>4.6%</td>
</tr>
<tr>
<td>Fall et al</td>
<td>13%</td>
<td>27.5%</td>
<td>6%</td>
<td>16%</td>
<td>8%</td>
</tr>
<tr>
<td>D’Amelio et al</td>
<td>27%</td>
<td>35%</td>
<td>20%</td>
<td>22%</td>
<td>7%</td>
</tr>
<tr>
<td>Beyer et al</td>
<td>13%</td>
<td>21%</td>
<td>9%</td>
<td>10%</td>
<td>17%</td>
</tr>
<tr>
<td>North Tyneside population (IPD)</td>
<td>12%</td>
<td></td>
<td>9%</td>
<td>-</td>
<td>12%</td>
</tr>
</tbody>
</table>
1a on the Death Certificate was pneumonia in 45%.

Nath et al – commonest cause of death in patients with PSP was pneumonia, occurring in 45% of patients.
## Death certification

<table>
<thead>
<tr>
<th>PD mentioned on Death certificate</th>
<th>89 (63%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PD NOT mentioned on Death certificate</td>
<td>53 (37%)</td>
</tr>
</tbody>
</table>

**Other Research**
- Beyer et al (2001) – PD mentioned in 50-60% of pts
- Nath et al (2005) – PSP mentioned in 65% of patients with known PSP
Trends in place of death (UK)

- Cancer deaths at home – falling
  - (1974 – 31.2%; 2003 – 22.1%)
- Non cancer deaths at home, - falling
  - (1974 – 31%; 2003 – 16.7%)

- Future predictions – by 2030 <10% die at home

- Implications for service provision
<table>
<thead>
<tr>
<th>Place of Death</th>
<th>General Population (age &gt;60yrs)</th>
<th>IPD - Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>HOME</strong></td>
<td>16.5%</td>
<td>12 (8.4%)</td>
</tr>
<tr>
<td><strong>CARE HOME</strong></td>
<td>20.6%</td>
<td>52 (36.4%)</td>
</tr>
<tr>
<td><strong>HOSPITAL</strong></td>
<td>58.7%</td>
<td>79 (55.2%)</td>
</tr>
<tr>
<td><strong>HOSPICE</strong></td>
<td>2.7%</td>
<td>0</td>
</tr>
</tbody>
</table>

Palliative care guideline adherence in people dying with PD in Northumbria

- Idiopathic PD under the care of the Northumbria PD service
- Died 1/1/08 to 31/12/11 (Northumberland) and 31/12/10 (North Tyneside)
- Retrospective case note review
- Place of death
- Use of Liverpool Care Pathway (LCP)

1 Walker R et al. Palliative care in people with idiopathic Parkinson's disease who die in hospital. BMJ Supportive and Palliative Care 202; 0: 1-4. doi. 10.1136/bmjspcare-2012-000412
Results

- Average age at death 82.8 years
- 110 (46.6%) died in hospital, 56 (23.7%) at home and 59 (25%) in a care home with unrecorded in 11 (4.7%)
- Of those dying in hospital 46 (41.8%) were placed on the LCP
- Median time on LCP prior to death (in hospital) was 2 days for Northumberland and 1 day for North Tyneside
Advance Care Planning (ACP)
Planning for the end of life (UK)

- Current DoH initiative that everyone with a long term condition (LTC) should have the opportunity to make an ACP
- Lots of questions
- By whom, with whom, when, where?
- What? – NB Lasting Power of Attorney (LPA), Advance Decision to Refuse Treatment (ADRT), Advance Statement
- How documented?
ACP in PD

- Those with PD are less likely to be aware of imminent death and have fewer visits from professionals compared to those with ALS.

- Proxy care reports are unreliable.

- Less than half of PD patients died where they desired compared to 76% of those with ALS.

- Despite PD patients (79%) indicating a desire for comfort care only for the last month of life, a quarter of PD patients had a feeding tube, and similarly a quarter required breathing support in the last month of life.

- Half of PD patients unable to make decisions in last month of life – 68% difficulty communicating, 47% confused.


Challenges of ACP in PD

- Inexorably progressive condition with great individual variability in the rate of disease progression and the problems which develop.

- Challenges in applying palliative care principles to those with non-malignant diseases whom may not wish to identify themselves as having a terminal illness, in whom the disease trajectory may be long and uncertain.
North Tyneside questionnaire

- Duration of PD: 15% < 1 year, 46% 2-5 years, 21% 6-10 years, 19% > 10 years
- 77% not aware of ACP but most wanted to know more
- 82% had made a will
- 25% had LPA in place (NB cost)
- More than 90% had not discussed wishes with health professional, other professional (eg solicitor) or recorded in writing
Typical case

- Man aged 78 - PD for 16 years with recent cognitive decline
- Recurrent admissions – falls, chest infections, urinary tract infections with associated hallucinations and increased confusion
- Now admitted unable to swallow – NG tube
- Discussions with family about artificial feeding (PEG tube) and where patient should be cared for
- What would the patient have wanted?
Take home messages

- Palliative care type symptoms common
- Hard to predict timing of death – NB weight loss
- Impaired swallow commonly related to cause of admissions, and death – NB aspiration pneumonia, difficulty providing dopaminergic medication
- Half of patients die in hospital
- Consider ACP – NB cognitive impairment and lack of capacity
Thank you
Questions

- Place of PEG tubes in complex PD patients with swallowing problems?
- What to do in patients who have lost “capacity”? 
- Brain donation – when, and who, to ask?
North Tyneside questionnaire

- 195 questionnaires (68% response rate) – 104 completed and 29 blank or undecipherable
- Happy to be interviewed - 61, 44 (patient and carer) and 17 happy (just patient or carer)