Place of Death for Parkinson Patients in an Ambulatory Palliative Care Clinic

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Potential COIs

- Research Grants: Teva, Abbott
- Consultancy: Novartis (DSMB), UCB Pharma, Merz
- Speaking: Teva
Objectives

1. Understand the disease trajectory in Parkinson's disease
2. List the common causes of death in Parkinson’s disease
3. List hospitalization challenges for Parkinson’s disease
4. List the signs of imminent death in Parkinson’s disease
WHO Principles of Palliative Care

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates psychological and spiritual aspects of pt care
- Offers support to help the family cope
- Uses a team approach to address needs
- Will enhance quality of life and may positively influence the course of illness
- **Is applicable early in the course of illness**
Theoretical Trajectories of Dying

Unmet Palliative Care Needs

- **DETERIORATING HEALTH STATUS**
  - Decreased Independence
    - Social Isolation
      - Limited Resources Available
    - Family Burden
      - Poor access to Community Services

- Acceptance
  - Concerned about Future
  - Depression

Fitzsimmons Palliative Medicine 2007
### Progression over 8 y

<table>
<thead>
<tr>
<th></th>
<th>Baseline</th>
<th>4y</th>
<th>8y</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hoehn and Yahr</td>
<td>2.8</td>
<td>3</td>
<td>3.4</td>
</tr>
<tr>
<td>Schwab and England</td>
<td>70 (Not completely independent. 3-4x N)</td>
<td>60 (dependency, some tasks impossible)</td>
<td>55 (help with nearly ½ all self-care)</td>
</tr>
<tr>
<td>MMSE</td>
<td>24</td>
<td>23</td>
<td>19</td>
</tr>
</tbody>
</table>

Alves Neurology 2005:65:1436-41
ER admissions over 4 years

<table>
<thead>
<tr>
<th>Reason for admission</th>
<th>Primary (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Falls</td>
<td>41 (17)</td>
</tr>
<tr>
<td>Pneumonia</td>
<td>32 (13)</td>
</tr>
<tr>
<td>Decreased mobility/dyskinesia</td>
<td>19 (8)</td>
</tr>
<tr>
<td>Angina</td>
<td>19 (8)</td>
</tr>
<tr>
<td>Heart failure</td>
<td>14 (6)</td>
</tr>
<tr>
<td>Surgical</td>
<td>13 (5)</td>
</tr>
<tr>
<td>UTI</td>
<td>12 (5)</td>
</tr>
<tr>
<td>Delirium</td>
<td>12 (5)</td>
</tr>
<tr>
<td>Orthostatic hypotension</td>
<td>11 (4)</td>
</tr>
<tr>
<td>Hallucinations</td>
<td>8 (3)</td>
</tr>
</tbody>
</table>

N = 367

Woolford Movement Disorders
2005
**Median Acute Care Length of Stay for Patients With Parkinson’s Disease in Canada, 2004–2005**

The median length of stay (LOS) for patients with PD was 10 days, compared with 4 days for all patients in acute care aged 19 and older. When PD was the primary diagnosis, the median LOS was 14 days.

**Note:** Based on patients 19 years of age and older.
Survival curves by duration PD

Figure 1. Survival in 230 community-based patients with Parkinson disease (PD).

Forsa et al
Neurology
2010;75:1270-6
Characteristics by QII

- National Parkinson Foundation Quality Improvement Initiative
- Baseline data presented and pt followed annually
- Total 4622 >10y duration 1835
- Mean duration 14 years (11-18)
- Mean onset 52.7 years, Current age mean 67.8 y
Characteristics continued

- **PD Diagnosis/Stage**
  - 1 Unilateral: 52 (3%)
  - 2 Bilateral: 706 (41%)
  - 3 Postural Impairment: 694 (40%)
  - 4-5 Requires Assistance: 272 (15.8%)

Or bedbound
- 75% relief in a spouse caregiver
- 5% had paid caregiver
- 93% lived at home
- MOCA 23.5 (+/- 3.8)
- 22% had DBS
- Caregiver Strain – highest for social isolation, physical, time, interpersonal strain
CamPAIGN Study: UK (2014, JNNP)

- N = 142, 121 PD, 21 died prior to diagnostic confirmation
- Of the surviving 121, 55% mortality at 10 years, mostly from aspiration pneumonia
- 40% of death certificates did not mention PD
Palliative Care in People with Parkinson’s disease who die in hospital

- UK study (BMJ Support Palliat Care) 2014
- N=236
- Over a 3 year period, 47% died in hospital
- 25% in a care home
- 14% were referred for Palliative Care
- 42% were placed on the Liverpool Care Pathway
Place of death and its relation with underlying cause of death (Palliat Med 2013)

- Hospice 0.6% PD, 27% hospice ALS
- Home death 10% in PD, 27% for Motor neuron disease
- Care home 46%, acute hospital 43%
Predictors of ER Visits or Hospitalizations for Palliative Patients Ontario

- More likely to visit ER if spouse is main caregiver
- Lower home care costs
- Pain rarely the cause
- Acute worsening > steady decline
- Less likely if expressed wish to die at home or Advance Directive (-.36 and -.27)
PD Palliative Team

- Movement disorders neurologist
- Palliative care specialist – Roger Ghoche, MD
- RN movement disorders – Janine Long, RN
- Care coordinator – Deb Mancini, BSc, MSc
- Spiritual advisor – Rena Arshinoff
Toronto Western Hospital Parkinson Disease Palliative Care Program

- H and Y > 2.5
- PD and parkinsonism (PSP, MSA, HD, neurodegen nfs)
- Assess pts and caregivers
- Provide referral to community services
- Address pain
- Discuss advanced care directives and power of attorney designation
TWH Movement Disorders Centre

- Largest centre in Canada
- 7 full time movement disorders neurologists
  - Investigators, scientists
- 4 RNs, 4 research coordinators
- >8000 patient visits/year
- 3500 novel pts
- Active surgical program – currently following 500+ DBS
Clinic Activities

Visit 1
- Baseline data
- Nursing assessment and education (skin care, bowels)
- MD assessment/pain management
- Spiritual counseling
- Introduce planning, directives, POA

Visit 2
- Nursing assessment
- Assess pain
- Discuss code status, what to do at home, planning, det POA
109 patients, 65 with more than one assessment

Mean Age 68 y (46-80y)

Duration of illness X = 14 (3-34y)

Hoehn and Yahr X = 5, Median 5 (3-5)

UPDRS III 40 (17-80)

MoCA score 11.5 (0-27)
<table>
<thead>
<tr>
<th>Symptom</th>
<th>Scale</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>No pain</td>
<td>0-10</td>
<td>Worst possible pain</td>
</tr>
<tr>
<td>Not tired</td>
<td>0-10</td>
<td>Worst possible tiredness</td>
</tr>
<tr>
<td>Not nauseated</td>
<td>0-10</td>
<td>Worst possible nausea</td>
</tr>
<tr>
<td>Not depressed</td>
<td>0-10</td>
<td>Worst possible depression</td>
</tr>
<tr>
<td>Not anxious</td>
<td>0-10</td>
<td>Worst possible anxiety</td>
</tr>
<tr>
<td>Not drowsy</td>
<td>0-10</td>
<td>Worst possible drowsiness</td>
</tr>
<tr>
<td>Best appetite</td>
<td>0-10</td>
<td>Worst possible appetite</td>
</tr>
<tr>
<td>Best feeling of wellbeing</td>
<td>0-10</td>
<td>Worst possible feeling of wellbeing</td>
</tr>
<tr>
<td>No shortness of breath</td>
<td>0-10</td>
<td>Worst possible shortness of breath</td>
</tr>
</tbody>
</table>
ESAS-rPD

- No Stiffness
- No constipation
- No difficulty swallowing
- No confusion

- Worst possible stiffness
- Worst possible constipation
- Worst difficulty swallowing
- Worst possible confusion
- My sleep is disturbed
- Caregiving is inconvenient
- Caregiving is a physical strain
- Caregiving is confining
- There have been family adjustments
- There have been changes in my personal plans
- There have been other demands on my time
- There have been emotional adjustments
- Some behaviour is upsetting
- It is upsetting to find pt has changed so much
- There have been work adjustments
- Caregiving is a financial strain
- I feel completely overwhelmed
Caregiver strain

- Measure through the Modified Caregiver Strain Scale – no difference between first and second visits
Zarit Caregiver Burden

- Do you feel your relative asks for more help than he needs?
- Do you feel because of caregiving, you don't have enough time for yourself?
- Do you feel stressed between caring for your relative and meeting other responsibilities for family or work?
- Do you feel angry when you are around your relative?

0 Never  4 Nearly Always
- Has your relative been physically aggressive with you or others?
- Has your relative made unwanted sexual advances towards you or others?
Interventions

- In home care (gov’t funded and private)
- Physiotherapy
- Swallow and Nutrition consultation
- Wound care nurse
- Botulinum toxin injection
- Pain management
- Psychosis/anxiety management
- Aggressive constipation treatment
Referrals and Services

Referrals = SLP, PT, OT, Nutrition, Gen Surg, Alz Society, Neurosurgery
Medications Added to Existing Regimen
180 patients: 39 deaths

Place of death: LTC 4
- Home 25 (community palliative care)
- Palliative inpt unit 4
- Acute care hospital 6 (no hospice bed 1)

Cause of death: aspiration pneumonia 26
died in sleep 5
other 2
ESAS-PD improved significantly (56 to 40) and to similar extent as those with endstage metastatic cancer 48 to 39) (p < 0.0001 (95% CI 10, 21)

Symptoms responding most to interventions were Dysphagia, constipation, anxiety, pain, drowsiness and other

Zarit Caregiver Burden Scale (modified) improved from mean V1 43.5 to V2 36 (p < 0.0001, 95% CI 6, 9) (max score 96)
Zarit Caregiver Burden Scale

- Our scale modified to ask
  - Has your relative been physically aggressive towards you or others?
  - Has your relative made unwanted sexual advances towards you or others?
- 50% responded 1 (rarely) or higher (4 always)
  - 21/52 physical aggression 7/52 sexual advances
Future plans

- Establish palliative care at the Kaye Edmonton Clinic Movement Disorders program
- Link with Dr. Wendy Johnston to provide Palliative Care for Complex Neurologic Symptoms (CNS Clinic)
- Provide in-hospital consultation for neurologic patients throughout UAH
- Provide support for Primary Care Networks providing palliative care in the community – including education if they wish
- miyasaki@ualberta.ca  Text 780 399 5800
Our Team

In Clinic:
• Deb Mancini MSc
• Janine Long RN
• Roger Ghoche, MD
• Rena Arshinoff

In hospital:
• Deb McGarvey
• Sherry Darling

In the Community:
• The Tammy Latner Centre
• Community Care Access Centre
• Alzheimer Society
• Rebecca Gruber and Jan Goldstein
• Dr. Joyce Lee, NYGH

Funding for the Centre
• National Parkinson Foundation
• The Rosati Family
• NORUS
• Parkinson Society Canada