Palliative Care for Parkinson's Disease

PADRECC, May 13, 2010
Elizabeth Goy, PhD
Lissa Brod, MD
Teresa Mangin, MD
Objectives

• To describe the end-of-life needs of Parkinson’s disease patients and their caregivers

• Describe translations of these findings into quality clinical care for people with Parkinson’s Disease

• Understand implications for multidisciplinary involvement in PD palliative care (Nutrition, PT, OT, ENT, Speech Therapy, Psychiatry, Psychology)
Definition of Palliative Care

• Support of people with life-limiting illness as they live, until they die.
  – Physical symptom control
  – Avoid iatrogenic effects of treatment
  – Prevent pressure sores, falls
  – Quality of life
  – Dignity
  – Relieve fear, anxiety, depression
  – Caregiver support
The clinical characteristics of PD create challenges to good palliative care

• Parkinson's Disease (PD) is a progressive neurodegenerative disorder
  – Loss of cells from substantia nigra, Lewy body inclusions
  – After ~ 5-10 years dyskinesias, neuropsychiatric problems, increasingly poor response to drug treatments, ongoing or worsening depression.
  – Slower progression for early onset, more rapid for older adults.
  – Average length of life with PD 14.6 (+ 9.8) years since advent of levodopa*

*MacMahon, 1999
Recognizing When to Transition to a Palliative Approach

• Increasing motor disability with poor response to medication/surgical intervention
• Persistent hallucinations in the absence of drugs that could cause hallucinations
• Dementia, where risk of cognitive compromise outweighs motor benefits of dopaminergics
Negotiating the Transition

• Understand individual preferences for information
• Frequent discussions with patients and family/caregivers
  – Who should initiate these discussions?
  – Multidisciplinary approach could be helpful
• Communicate known limitations of treatment (e.g. drugs will not prevent falls, DBS may not be appropriate intervention in context of significant neuropsychiatric symptoms/dementia)
Do people die from PD?

- Often not cited on death certificates, neurology textbooks equivocal
- PD was the 14th leading cause of death in the U.S. in 2006 per CDC
- Common cited causes for PD patients include:
  - Fractures, complications from falls
  - Chest and urinary infections
  - Immobility
  - Exhaustion/weight loss
- Goy, Carter, & Ganzini reported (Neurology 2007) on 47 caregivers who described PD as primary cause of death.
Hospice Referral

- MD verifies six months or less remaining lifespan
- No further curative treatment
- Palliative approaches to symptom management, comfort care
Appropriate Hospice Referral

- Significant dysphagia occurs an average 15-24 months before death\(^1\)
- Serious neuropsychiatric problems\(^2\)
  - Hallucinations
  - Confusion
  - Dementia
- PD medications significantly reduced\(^3\) due to altered risk/benefit profile
- Weight loss\(^3\) – secondary to reduced intake and dyskinesia

\(^1\)Miller et al., Arch Neurol 2001;58:259-264; \(^2\)Clough & Blockley in Palliative Care Neurology, Voltz et al., eds., 2004; \(^3\)Goy, in preparation
End-of-life needs of Parkinson’s disease patients and caregivers

Lissa Brod, MD
Motor Complications of Late Stage PD (Hoehn-Yahr Stage 5)

- Freezing
- Rigidity
- Dyskinesia
- Dysarthria
- Dysphagia
- Respiratory problems
- Less response to dopaminergic medicines
- Pain
Nonmotor Complications of Late Stage PD (Hoehn-Yahr Stage 5)

• Cognitive slowing
• Dementia – 40% develop in late stages
• Psychosis/hallucinations
• Depression, anxiety
• Dysregulation of blood pressure
• Dysregulation of bowel/bladder - constipation
• Sleep disturbance
Patient suffering in PD

• Severity of suffering 4 (out of 5) in both Parkinson’s disease and related disorders (PDRD) and ALS in the last month of life
  – Difficulty communicating, physical discomfort, insomnia, choking, depression, anxiety, pain
  – Difficulty eating, dyspnea worse in ALS
  – Confusion worse in PDRD

Patient suffering in PD

• Most common concerns in last month, per caregivers: being away from home (9), loss of mobility (7), trouble communicating (7), saying goodbye (7), dying process (confronting death, stopping treatment) (6), loss of independence/control (5).

• Most common concerns in last days/hours, per caregivers: inability to communicate (14), loss of mobility (9), saying goodbye (8), being away from home (6), loss of independence/control (6), confusion (6).

Table 1. Caregiver Ratings of PDRD (N = 52) Patient Symptoms in the Final Month of Life

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>Frequency* (Median, IQR)</th>
<th>N (%) Rated Symptom Moderate or Severe</th>
<th>N (%) Rated Symptom “Quite a Bit,” or “Very Much” Bothersome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty Eating</td>
<td>3 (2,4)</td>
<td>34 (65)</td>
<td>23 (44)</td>
</tr>
<tr>
<td>Difficulty</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communicating</td>
<td>3 (2,4)</td>
<td>37 (71)</td>
<td>32 (62)</td>
</tr>
<tr>
<td>Physical Discomfort</td>
<td>3 (2,3)</td>
<td>33 (63)</td>
<td>19 (37)</td>
</tr>
<tr>
<td>Insomnia</td>
<td>2 (1,3)</td>
<td>22 (42)</td>
<td>16 (31)</td>
</tr>
<tr>
<td>Shortness of Breath</td>
<td>2 (1,3)</td>
<td>24 (46)</td>
<td>15 (29)</td>
</tr>
<tr>
<td>Choking</td>
<td>2 (1,3)</td>
<td>22 (42)</td>
<td>18 (35)</td>
</tr>
<tr>
<td>Confusion</td>
<td>3 (2,4)</td>
<td>32 (62)</td>
<td>22 (42)</td>
</tr>
<tr>
<td>Depressed Mood</td>
<td>3 (1,3)</td>
<td>28 (54)</td>
<td>17 (33)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>2 (1,3)</td>
<td>28 (54)</td>
<td>18 (35)</td>
</tr>
</tbody>
</table>

* 1 = never, 2 = a few times, 3 = frequently, 4 = almost all the time, 5 = constantly.
Pain in PD

• Musculoskeletal causes
  – Immobility
  – Muscle spasms

• Motor complications
  – Limb rigidity
  – Dystonia

• Nonmotor complications

• Altered nociception from the basal ganglia
• Median Severity = 4
• 42% (n = 20) rated pain as severe (4-6)
• Of those, 30% (n = 6) received NO pain medication in the last month of life
Caregiver Assistance to Loved One

• Assisted with a mean of 13 possible activities of living in the last months of life, a mean of 6 hours per day.
• Tasks requiring physical effort were rated the most difficult.
• One third or more of respondents did not feel prepared to cope with the stress of caregiving, with the patient’s physical needs, or with emergencies.
• High incidence of depression in PD caregivers (46%). No significant difference from ALS caregivers.
legend

- Very hard
- Somewhat-Pretty hard
- Easy-Not too hard
- Not done
Long Term Care

• 40% of PDRD patients died while in a skilled nursing or other long term care facility; only one in four died at home.

• 17% of PDRD residents of long term care facilities died without any significant family or friends in attendance, while all who remained at home had at least one significant person with them (p = .006).
Goals of Care

- 15% of PDRD caregivers were unable to state loved one’s goals of care.
- 48% of the patients were described as unable to make any decisions in the last month of life.
- Caregivers rated less satisfaction with answers received from health care professionals as patient confusion increased in frequency, patients had greater impairment of decision-making ability during the last month of life, and as a trend, when communication problems were increasingly severe.
Goals of Care

- 87% had a health care proxy and 92% had a living will.
- 79% wanted comfort care, 6% life-prolonging.
  - CPR was not performed on any patient,
  - 26% were fed by tube and
  - 30% received some type of breathing support.
- Most (74%) felt wishes regarding medical treatments were followed.
Goals of Care

• When should providers discuss this?
  – Supporting hope vs realistic planning
  – Prognostic uncertainty
Services, Treatments during Final Month

- Fifty-six percent of PDRD caregivers reported that their loved one received hospice care, for a median of three weeks.
  - More likely to receive pain medication in hospice.
Hospice

• Satisfaction with hospice care was at the top of the ranking for satisfaction with health care (24 of the 29 who received hospice were satisfied or very satisfied).

• Among the patients enrolled in hospice, increasing severity of complicated grief was correlated with satisfaction with hospice (p = .002).

• Increasing satisfaction with information provided about symptom management was associated with greater satisfaction with hospice services (p < .01).
What Would the Ideal Palliative Care Clinic Look Like for Parkinson’s Disease?

Teresa Mangin, MD
Challenges Addressed by a Palliative Approach

- Unrealistic expectations on the part of patients and caregivers
- Caregiver burden
- Existential suffering
- Pain
- Psychosis
- Dysphagia and nutrition
- Communication problems
- Constipation
- Medication management
Members of the Ideal Palliative Care Team

• The patient
• Caregivers and families
• Nurse
• Social Worker
• Physicians – neurologist, palliative care specialist, psychiatrist, others
• Speech therapist
• Physical and occupational therapists
• Psychologist
• Nutritionist
• Chaplain
Unrealistic Expectations

• Breaking the news that PD may result in death
• Helping families plan for inevitable decline in function
• Teaching the limits of medications and their specific roles
  – Tension between motor and cognitive function
Caregiver Burden

• Screening for caregiver strain or burden in clinic
• Providing support
  – Asking about this at each visit
  – Peer support over the phone if unable to leave pt
• Facilitating home help, both formal and informal
• Day programs for patient
• Offering programs geared toward caregivers (cognitive behavioral therapy, support groups)
Existential Suffering

• “a perceived threat to the integrity of the self, helplessness in the face of that threat, and exhaustion of psychosocial and personal resources for coping” -EJ Cassell

• Expressed by patients as feelings of hopelessness, futility, meaninglessness, remorse, death anxiety

• Leads to suffering and frustration on the part of the family
Existential Suffering: Some Truths

• This is normal and need not be totally controlled.
• There is no effective drug therapy.
• It leads to frustration in families and providers.
• Recognition of the factors involved in the individual patient helps to understand how to meet their needs.
• Relieving the suffering of the patient helps caregivers and providers.
• There is a distinction between fear of the dying process and fear of being dead.

Lieberson 1999 *Treatment of Pain and Suffering in the Terminally Ill*
Existential Suffering

• Treatment of attendant symptoms of pain, anxiety, depression, etc.

• Acceptance commitment therapy (ACT)
  – Branch of cognitive behavioral therapy
  – Incorporates mindfulness, acceptance, commitment and behavior change strategies to improve psychological flexibility

• Preserving patients’ dignity
Pain

• Fear of pain is a common source of distress.
  – Relief of pain may take precedence over prolongation of life.
  – Reassure patient that his/her wishes will be honored and that pain will be controlled.
  – Identify and address fear of pain medications.
• Pressure sores
• Dystonic pain
  – May consider botulinum toxin injections
• Musculoskeletal pain
  – ROM exercises
• Ideally, have a pain management specialist in clinic with the neurologist.
  – Toronto Western Hospital
Management of Psychosis

• Streamlining medication regimen
• Reduction of dopaminergic medications
• Communicating with care facilities about preferred medications in PD
• Do not be afraid of clozapine!
• Psychiatry referral
Dysphagia

- ENT speech therapy for modified barium swallow
- Rehab speech therapy for teaching management strategies (chin tuck)
- Clarifying patient’s wishes if swallowing is unsafe
- Discussion of and referral for G-tube if necessary and desired
- Nutrition consult
Communication Problems

• Often multifactorial in nature due to hypophonia, cognitive problems, bradyphrenia

• Lee Silverman Voice Therapy

• Enlisting speech therapist for communication board, other tools

• Allowing sufficient time for patient to respond
Medication Management

• Identifying priorities with respect to medication
• Simplifying regimen
• Eliminating medications that can contribute to cognitive side effects
• Educating about role of various medications (including those that are relatively contraindicated in PD)
• Strategies for medication reminders
References

• Clough & Blockley in Voltz et al., eds., Palliative Care Neurology, 2004
• Lieberson 1999. Treatment of Pain and Suffering in the Terminally Ill
• Miller et al., Arch Neurol 2001;58:259-264;
Thanks to our Collaborators

• Julie Carter RN
• Linda Ganzini MD, MPH
• Molly Delorit, BA