LATE STAGE PARKINSON’S DISEASE

INTRODUCTION

Scope of PD
What comes before late-stage PD; general principles of each stage
Characteristics of late-stage PD
Team-based care
Medical care

PD IS A COMMON DISEASE

Common disorder in the elderly
- 1 million affected in the US
- Affects 1% of people over 60
- 50,000 new cases/year in the US
- Present in 2-10% of LTC residents
Chronic disorder
- Average course 15 years
Wide range of effects

The burden of Parkinson disease and other neurodegenerative conditions is growing

Distribution of individuals with Parkinson disease by country from 2005 to 2050

CARE-DEFINING CHARACTERISTICS OF PD

Neurologic disease
Adult-onset disease
Chronic disease
Many causes
PRINCIPLES OF CARE

- Nobody can “do” PD alone
- Care from beginning to end
- Support and education
- Proactive care

IMPLICATIONS OF THE DIAGNOSIS

- PD is slowly progressive, over years-decades
- Motor symptoms are treatable
- Not curable yet
- More people die “with” PD than “of” PD
- Optimal function requires the right medications, taken correctly, education about the disease, exercise, healthy living, energy and stress management, good general health

MOTOR SYMPTOMS OF PD

- Rest tremor, usually unilateral at onset
- Bradykinesia (slowness of movement)
- Rigidity (muscle stiffness)
- Postural instability (imbalance)

NON-MOTOR SYMPTOMS

- Memory impairment
- Depression/anxiety
- Low volume speech
- Sleep dysfunction
- Swallowing difficulty
- Pain
- Constipation
- Anosmia
- Skin changes
- Statorrhoea
- Urinary frequency

THE COURSE OF PD

- Early PD: Primary motor symptoms, medications work well, mild disruption in lifestyle
- Mid-stages of PD: Other symptoms emerge, medications wear off, medications have side effects, moderate disruption in lifestyle, still living at home
- Late PD: Symptoms are severe, needs daily care help, may have dementia, may be unable to live at home

STAGING SYSTEM — HOEHN AND YAHN

- Stage 0: No signs of disease
- Stage 1.0: Symptoms are very mild, unilateral involvement only
- Stage 1.5: Unilateral and axial involvement
- Stage 2.0: Bilateral involvement without impairment of balance
- Stage 2.5: Mild bilateral disease with recovery on pull test
- Stage 3: Mild to moderate bilateral disease, some postural instability, physically independent
- Stage 4: Severe disability; still able to walk or stand unassisted
- Stage 5: Wheelchair bound or bedridden unless aided
EARLY PD

Wellness (Nutrition, exercise, spiritual health)
Education about the disease
Involvement in research
Advocacy
Maximizing good function as long as possible with as little medicine as possible

PARKINSON MEDICATIONS

Carbidopa/levodopa
- Immediate release
- Controlled release (Sinemet CR)
- Novel controlled release (Rytary)

Dopamine agonists
- Pramipexole (Mirapex) – immediate or controlled release
- Ropinirole (Requip) – immediate or controlled release
- Rotigotine patch (Neupro)
- Apomorphine injection

PARKINSON MEDICATIONS (CONTINUED)

COMT inhibitors
- Entacapone (Comtan)

MAO-B inhibitors
- Selegiline
- Rasagiline
- Safinamide

Amantadine
Anticholinergics: trihexyphenidyl, benztropine, etc.

MID-STAGE PD

DBS surgery?

Career, leisure, financial, medical care planning

Assemble a team of medical care providers

Identify, educate, and support future caregivers

NEW LEVODOPA PRODUCTS

Duopa (carbidopa/levodopa intestinal gel)
- Gel infused over 16 hours via tube into small intestine. Good for patients with fluctuations who aren’t candidates for other therapies like DBS surgery

Rytary (carbidopa/levodopa extended release)
- Allows for less peaks and valleys in dopamine levels, good for people who have fluctuating symptoms or dyskinesia

Parcopa (oral-dissolving carbidopa-levodopa)
- Helpful for people who might have trouble swallowing a pill but can swallow their own saliva

DEEP BRAIN STIMULATION FOR PD

Pacemaker-like technology to deliver electrical impulses to targeted structures in the brain

Electrical pulses block brain signals that cause PD symptoms

Implanted device can be programmed non-invasively to optimize benefits and minimize side effects

Therapy is reversible, preserving options for the future
**LATE-STAGE PD**

- Safety
- Quality of life
- Minimizing disease burden
- Minimizing treatment burden
- Preparing for the end

**GENERAL PRINCIPLES OF MEDICATION MANAGEMENT OF PD IN LTC**

- Prioritize the symptoms!
- Simplify the med list!

- Timing of levodopa (and other PD meds) can be critical
  - Selegiline and amantadine cause insomnia
  - Pramipexole and ropinirole cause sleep
  - All PD meds promote hallucinations
  - "wearing off", "motor fluctuation", dyskinesia
  - Levodopa is the most effective drug, with (generally) the least side effects

**CASE DISCUSSION**

80 yo pt admitted to LTC after admission for pneumonia, FTT. PD for 10 years, taking pramipexole 0.75mg once a day, CR carbidopa-levodopa twice a day, and IR carbidopa-levodopa three times a day.

A week later, family says she can’t move well, is sleepy during the day and is hallucinating and can’t sleep at night.

**RESOLUTION**

- It turns out that….
  - In the facility, she was getting pramipexole at 8am, CR levodopa at 8-8, and IR levodopa at 8-2-8.
  - At home, she was supposed to take pramipexole at bedtime but had stopped it 6 months ago, IR levodopa was at 8-12-4, and CR was at 8-8.
  - Levodopa administration times were adjusted back to the home schedule and pramipexole was stopped. Nighttime pain was controlled with tylenol, and an SSRI was started for depression. She was engaged in PT, OT, and speech therapy, and 3 months later, had gained 5 pounds, was walking daily, and felt stronger than she had for 2-3 years!

**CHALLENGING ISSUES IN LATE-STAGE PD**

- Autonomic dysfunction
- Dyskinesia/motor fluctuations
- Dementia
- Voice/communication issues
- Sleep issues
- Psychiatric issues
- FALLS
  - Patient and family acceptance of disease progression/med changes (reductions)
  - Communication among providers

**AUTONOMIC DYSFUNCTION**

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Management</th>
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<tbody>
<tr>
<td>Constipation</td>
<td>Diet, OTC medications</td>
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<tr>
<td>Urinary urgency</td>
<td>Toilet schedule, medications</td>
</tr>
<tr>
<td>Sweating (or lack thereof)</td>
<td>PD meds on schedule</td>
</tr>
<tr>
<td>Salivary issues (drooling)</td>
<td>Medications, botox</td>
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Prominent early autonomic symptoms may suggest a diagnosis of Multiple System Atrophy or Shy-Drager Syndrome.
ORTHOSTATIC HYPOTENSION

Defined as drop in systolic BP >20, diastolic BP >10 within 3 minutes of standing

- Reduce or stop antihypertensives
- Ensure adequate hydration, salt intake
- Compression stockings
- Stand up slowly
- Add fludrocortisone, midodrine, droxidopa, pyridostigmine

DRUG THERAPY FOR WEARING OFF

- Take levodopa more frequently (possibly at a lower dose)
- Try carbidopa/levodopa ER (Rytary)
- Duopa (continuous levodopa pump)

Adjuvant agents:
- COMT inhibitor (entacapone)
- MAO-B inhibitor (rasagiline, selegiline)
- Dopamine agonist

Most people in advanced stage not candidates for DBS surgery (falls, dementia)

DYSKINESIA

Usually related to excessive levodopa
Sometimes occurs as levodopa is wearing off
Is not dangerous, ranges from mild to severe

Medication adjustments: smaller doses of levodopa, add amantadine, DBS

COGNITIVE IMPAIRMENT/DEMENTIA

In late stage PD, up to 70-80% of patients have dementia
Average duration of Parkinson’s disease diagnosis to onset of dementia around 10 years

Common cognitive phenotype:
- executive dysfunction
- bradyphrenia
- visuospatial dysfunction
- short term memory loss

COGNITIVE IMPAIRMENT/DEMENTIA

Treatment:
- consideration of acetylcholinesterase inhibitors (donepezil, rivastigmine, etc)
- limit neuroactive medications
- consider rehab therapy (probably more useful in earlier stages of dementia)
- stable daily routine
- physical, mental, social stimulation
**VOICE/COMMUNICATION ISSUES**

Work with speech therapy

Low-tech (or hi-tech) communication devices:
- Microphone, iPad with speech program; word board
- Expect dysphagia in people with speech problems

There can be breath control issues, which can also result in anxiety

**SLEEP DISTURBANCE**

Insomnia
Hypersomnia
Restless legs/periodic limb movements
REM behavior disorder
Sleep-disordered breathing

Evaluation may require formal sleep study
Good “sleep hygiene”, medications may help

**PSYCHOSIS**

Occur in about 45-65% with Parkinson’s disease dementia

Hallucinations can take different forms:
- Visual illusions (seeing object as something else)
- Fleeting images
- Well formed animals, people
- Tactile, auditory hallucinations

Delusions can include “feeling of presence”, paranoid, grandiose delusions

**PSYCHOSIS**

Treatment:
- reduce or eliminate non-levodopa medications (particularly dopamine agonists, anticholinergic medications, entacapone, etc)
- reduce levodopa if possible
- pimavanserin (Nuplazid)
- quetiapine
- clozapine

**DEPRESSION/ANXIETY**

Affects 40-60% of people with Parkinson’s disease

Treat directly, watch for agitation or behavior changes

High index of suspicion (common problem)

Anxiety can occur with wearing-off (and would then be treated with either levodopa or anxiety medicine)

**FALLS**

Motor disability and complications result in high risk of falls
Risk is 40-70% even when on optimal medications
More levodopa does not usually help balance

Potential causes of falls:
- Unsteady gait
- Postural instability
- Orthostatic hypotension
- Side effects of medications (antidepressants, benzos, etc)
- Disturbances of posture (apansicentric)
- Deconditioning/weakness
- Fear of falling
**DISEASE PROGRESSION**

Death will inevitably come
Dysphagia with weight loss or recurrent aspiration pneumonia; recurrent hospitalization are ominous signs
Hospice can be helpful

**PALLIATIVE CARE**

Can be offered/is helpful at most stages of Parkinson’s disease

Usually a focus on:
- physical: pain, breathlessness, anorexia, immobility and constipation
- social: loss of employment, role change, fear for dependents
- psychological: depression, fear and anxiety, uncertainty, guilt
- existential: religious, non-religious, meaning of life, why?

**ACCEPTING MEDICATION REDUCTIONS**

Make changes one at a time
 Someone has to make a determination of whether the person is better, worse, or the same after the med change (tell the nurse/patient/family what to look for!)

**MANAGING DYSPHAGIA/WEIGHT LOSS**

Malnutrition is common:
- difficulty feeding
- altered satiety mechanism
- diminished gastric and intestinal motility
- lack of appetite
- dysphagia
- metabolic syndrome

Speech therapy consult to ensure correct food textures, assistance
Dietary consult to ensure correct caloric offerings
Review of advance directives with spouse

**TEAM-BASED CARE IN A FACILITY**

MD: Neurologist, internist (NH specialist), NP (geriatrician), palliative care/hospice MD, psychiatrist, dentist
Floor nursing: RN, LPN, TMA, CNA
Rehab therapies: MT, OT, PT, RT, ST
Support: psychology, social work, chaplain
Other health support: dietitian, pharmacy, lab
Other services: maintenance, administration

**PARKINSON’S DISEASE—LONG-TERM CARE**

3-year mortality rate for people with PD in LTC is 50% (Fernandez 2002)
- CHF, diabetes, pressure sores, and pneumonia are independent predictors of death

Incorrect diagnosis of PD in 53/258 NH patients, (Weerkamp 2014)
Residents had 13 non-motor symptoms of PD using the NMSS, including 45% depression; irritability, apathy; 77% with PD dementia (Weerkamp, 2013)
LONG-TERM PROGNOSIS

Australian study of 136 pts over 20 yrs:
- 100/136 dead
- 91% freezing of gait
- 87% have fallen
- 83% dementia
- 81% dysarthria (48% choking)
- 74% hallucinations
- 70% daytime sleepiness
- 68% postural hypotension

HIP FRACTURE AND PD

Study in NY of 920 patients with hip fracture
- 3.4% (31) had a history of PD
  - PD pts were more likely male, dependent in ADLs, less ambulatory ability
  - PD pts were in hospital longer, and more likely discharged to NH
  - Post-op complications, mortality, recovery of ambulation were not worse

HOSPITALIZATION IN PD (246 ADMISSIONS TO METHODIST HOSPITAL)

Number of patients admitted
- Falls
- Pneumonia
- Urinary infection
- Mobility problems
- Psychosis
- Incontinence
- Heart failure
- Fracture
- Orthostatic hypotension
- Surgery
- GI bleed
- Stroke/TA

NURSING HOME PLACEMENT

More likely in people with PD (RR 6.1)
- Cognitive impairment, hallucinations, age, functional impairment predict NH placement
- Typical course until death is <3 yrs after NH placement

CHARACTERISTICS OF PD IN LTC

2002 study using MDS
- Identified 79,000 people with Parkinsonism in LTC
- Average age at admission: 79.7 years
- 66.4% male
- Physically dependent, depressed, and cognitively impaired
- >30% had falls in the previous month
- <10% received active or passive ROM treatment
- <10% had been evaluated by mental health specialist

DEATH

Recognize that the end is coming
Inform patient and family
- Hospice or hospice-like care can be helpful
- Strong focus on comfort, pain relief
- Engagement with the family
- Death details
- Support for family after death
- Staff and other residents grieve, too...
PRINCIPLES OF CARE

There is NEVER “nothing I can do”

STRUTHERS PARKINSON’S CENTER

A National Parkinson Foundation Center of Excellence