ALLIED TEAM TRAINING FOR PARKINSON
ROLE OF THE NURSE IN MIDDLE STAGE PARKINSON’S DISEASE PRACTICE
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Slides complements of JOAN M GARDNER, RN BSN

Disclosures for Susan Heath
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  • Consultant for AbbVie

Learner Objectives
• Describe the symptoms of Middle Stage PD
• Describe appropriate nursing interventions with middle stage PD
• Identify educational needs of patient/caregiver in middle stage PD
• Describe at least two tools used for assessment of depression in Parkinson disease
• Discuss the potential benefits of a structured caregiver assessment in Parkinson disease

Middle Stage PD-Hoehn and Yahr Staging
Stage I: Unilateral involvement
Stage II: Bilateral or Axial involvement without balance impairment
Stage III: Bilateral involvement
  Mild postural imbalance
  Patient leads independent life
Stage IV: Bilateral involvement
  Postural instability
  Patient requires help with activities of daily living
Stage V: Fully developed disease
  Patient restricted to bed or chair

Parkinson’s Disease Progression
(Bunting-Perry, 2007)

Middle Stage PD
• Greater impact of symptoms
  – More bothersome
  – Interfer with daily tasks
  – Require more assistance, less independence

• Medication schedules become more complex
  – May have multiple medications 4-6x/day

• Referral to the team members is essential, as medications will not help all symptoms

• Family involvement
  – Becomes necessary for family to attend medical appointments to understand plan
  – Sometimes family must be educated in Parkinson’s if they have not attended appointments
Multiple area/issues for team members

• Non-motor sx’s worsen
  – Sleep issues, mood issues, bladder issues, pain, cognitive

• Motor sx’s worsen
  – Ability to turn in bed, get in or out of a chair, bed or car
  – Freezing and /or gait changes
  – Balance impairment (near falls) or falls
  – Swallowing/choking fears

• Medication schedule complicated
  – Reliable organization system for pills
  – Medication complications (dyskinesias)

• Caregiver/family issues
  – Increased dependence, communication challenges ("one person is deaf and the other mumbles")
  – Coping strategies, support, resources

Additional concerns - Progresses in advanced PD

• Motor fluctuations
• Autonomic complications
• Sleep disturbances
• Sensory problems (pain, numbness, tingling)
• Cognitive impairments
• Anxiety
• Depression
• Apathy
• Hallucinations
• Increased carepartner burden

PD Medication Treatment: Some Potential Flows

Narrowing of the Therapeutic Window

The Levodopa Therapeutic Window Narrows with Disease Progression - less time with ‘perfect’ benefit

Teach the Parkinson’s Symptom “Lingo”

The patient/carepartner should learn terms: “wearing off”, “on/off”, “dyskinesia”

“Are you looking or waiting for your next dose of meds?”
Dyskinesia

**Dyskinesia** = uncontrolled writhing movement of the body or limb

- Dyskinesia needs to be assessed (when it occurs in the treatment cycle)
  - Peak dose (usual)
  - End of dose (wearing off, D-I-D)
- Tool: Dyskinesia Rating Scale

**Management strategies:**

- May give less levodopa more frequently
- May add dopamine agonist and decrease levodopa
- May add amantadine; may try newer med options

**Presentation Implications**

<table>
<thead>
<tr>
<th>Presentation</th>
<th>Implications</th>
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<tbody>
<tr>
<td>Peak “on”</td>
<td>Able to ambulate</td>
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<td>Self care for ADLS’s</td>
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<td>Often clearer thinking</td>
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<td>Understand what each patient “on” state looks like</td>
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<td>Wearing off</td>
<td>Return of PD motor symptoms</td>
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<td>Anxiety, mood changes</td>
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<td>Increase dose</td>
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<td>Increase frequency</td>
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<td>Add another medication</td>
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<td>Adjunct therapy (PT, OT, ST)</td>
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<tr>
<td>Freezing</td>
<td>Akinesia with step initiation, turning, changed environment</td>
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<td>Physical therapy for Physical cues (rocking, etc)</td>
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<td>Med adjustment</td>
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<tr>
<td>Dystonia</td>
<td>Sustained posturing of a limb that is painful and disabling</td>
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<tr>
<td></td>
<td>Early morning foot dystonia is common (curling of toes)</td>
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<td>Bottox, pain meds</td>
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<td></td>
<td>Physical, occupational therapy</td>
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<td>Med adjustment</td>
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<tr>
<td>Dyskinesia</td>
<td>Involuntary movement of UE, LE, trunk, head, (varies)</td>
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<td>Different from tremor</td>
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<tr>
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<td>Levodopa adjustment</td>
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<td>Add amantadine</td>
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<td>OT: fatigue management</td>
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<td>Dietitian</td>
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**Motor Fluctuations**

- Once “unpredictable” motor fluctuations occur they can be difficult to treat
  - Common in advancing PD
  - Sudden onset, often associated with freezing of gait (“FOG”)
  - Cognition and mood may also be affected
- Apomorphine, an injectable dopamine agonist for treating sudden or unpredictable “offs”
- Pt may be DBS candidate if meds improve motor function by minimum of 30% (off versus on) and cognitively ok (does not have to be perfect.)
Patient Med Diary

For each half hour time period, choose the description that best fits your experience during most of that time.

Option: None
1: No tremor
2: Mild tremor
3: Moderate tremor
4: Severe tremor

*Note: Each option is to be marked only once per time period.

Case Study

Pt. Diagnosed with Parkinson’s disease 2008
Current medications
- Carb/levodopa 25/100 1.5 tablets every 3 hours
- Pramipexole ER 1.5 mg
- Clonazepam 0.5 mg hs and prn bid

Motor symptoms
- Tremor-right sided despite meds
- Rigidity bilat in off state, wakes up slow and stiff
- Bradykinesia in off state
- FOG (freezing of gait - in med off state)

Non-motor symptoms and secondary symptoms
- Anxiety, Depression
- Painful ankle dystonia - wants to see Orthopedist
- Dyskinesia and spouse reports ICD behavior

Importance of Pills on Time

A visual chart outlining schedule is helpful to many

<table>
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<tr>
<th>Time</th>
<th>Carb/levodopa 25/100</th>
<th>Comtan</th>
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Complex Symptoms

Protein and Levodopa

The need for Pills on Time

Exact timing should be obtained from the ordering clinician
- Typical bid, tid, qid usually does not apply
- Should follow the same schedule daily
  - Pill boxes, timers, referral to OT
  - Teach patient / family self monitoring to relate symptoms to timing of medication
  - A frustration for all who are hospitalized or move to a residential living setting

For best absorption of levodopa avoid high protein foods within 30-60 minutes before and after

Some studies state 15% are negatively affected by protein

Requirements are 56 grams/day for men and 46 grams/day for women
**Protein and Levodopa**

If protein appears to be interfering with levodopa absorption, and/or the patient experiences motor fluctuations, a trial of charting the timing of c/l before or after meals for 2 weeks may be helpful.

Encourage use of a diary to monitor effectiveness

Scheduling mealtime away from pills is challenging if requiring frequent doses/day

Taking carb/levo with a carbonated beverage may result in faster absorption

Some chew tablets for a faster effect (parcopa - quick dissolving)

Should not chew or crush CR medications

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**Protein and Levodopa**

If protein sensitive:

- Consider portion size of protein containing food
- Experiment with plant vs. animal protein sources
- Eat the majority of protein in the evening
  - Protein redistribution diets (PRD) are at first followed but not long term
- Eat small frequent meals throughout the day
- Eat a low fat diet-fat further delays emptying

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**Deep Brain Stimulation (DBS)**

- An option for some when medications no longer provide sufficient quality of life
- Risk factors are low in experienced centers, not experimental
- The stimulator requires adjustment over time to maximize benefit to the patient.
- Batteries need surgical replacement. Average Q 3yrs

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**Before and After STN DBS**

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**Deep Brain Stimulation (DBS)**

- Nursing has a key role in patient/family education
- Many nurses in some centers programs the DBS
- Group classes regarding DBS pre-op teaching/candidacy
- Goal oriented individual teaching
  - What are your top 3 goals for DBS surgery?
  - What are your concerns regarding DBS surgery?
- Programming after surgery
- Required post-DBS follow-up
  - Programming and battery assessment
  - Med adjustments
  - Objective assessments / triage for rehab/support

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Hospitalization and Parkinson’s

- People with Parkinson’s are hospitalized 50% more than their non-PD peers
  - As a group, PD patients have more inpatient days over their lifetime following the diagnosis of PD when compared to the general population
- Length of hospitalization is 2-14 days longer than non-PD patients
- Usually admitted for other medical conditions

Gerlach OH et al, Clinical problems in the hospitalized Parkinson’s disease patient: systematic review, Movement Disorders 2011 Jan 31
National Parkinson Foundation working group on hospitalization in Parkinson’s Disease, Parkinsonism and Related Disorders 2011 Mar;17(3):139-145.

What to do if Hospitalized

Upon admission to hospital it is important for patient/family to advocate for their usual PD meds and dosing schedule

- With the patient/family, verify exact dosages and formulations (immediate release, controlled release, etc.) Hospital medication schedules (qid) are not same as home qid. Need to specify individual’s PD med times with hospital providers and nursing staff.
- Patient may need a dose of PD meds before meds are received from the pharmacy.

Story: Bill who forgot his hospital kit....

Resources

National Parkinson Foundation
- AWARE in CARE kit

www.awareincare.org
or
call 1-800-4PD-INFO (473-4636)

What’s in the Kit?

1. Aware in Care Bag—Pack your bag with your Parkinson’s medication and your Aware in Care materials
2. Hospital Action Plan—Read about how to prepare for your next hospital visit—whether it is planned or an emergency
3. Parkinson’s Disease ID Bracelet—Wear your bracelet at all times in case you are in an emergency situation and cannot communicate
4. Medical Alert Card—Fill in your card with emergency contact information and place in your wallet
5. Medication Form—Complete this form and keep copies
6. Parkinson’s Disease Fact Sheet—Share the facts about Parkinson’s with hospital staff and ask that a copy be placed in your chart
7. I Have Parkinson’s Reminder Slips—Share vital information about Parkinson’s disease with every member of your care team in the hospital
8. Thank You Card—Present this card to a staff member who provides high quality care
9. Magnet—Use this magnet to display a copy of your Medication Form in your hospital
Considerations for inpatient stays

- Instead of NPO after midnight, give PD pills with a small sip of water right up to time of procedure.
- Restart PD pills as soon as able to swallow following a procedure.
- Dissolvable form of carbidopa/levodopa (Parcopa®) may be useful in some patients after a procedure or if swallowing difficulties.
- Story: Neurologist from small hospital called about unresponsive pt in their ICU.

Considerations for Care During Hospitalization

- Plan nursing care/activities after medications have ‘kicked in.’
- If medications have to be crushed and administered through a tube, give them at least one hour prior to meals.
- If medications have to be crushed and administered through a tube, they will convert to immediate release levodopa.
- Avoid delirium if general anesthesia is used.
- Narcotics, muscle relaxants, bladder, sleep and pain medications can increase the risk of confusion, hallucinations or delirium.
- If patient becomes confused, consider urinary or lung infection as possible cause.

Contraindicated Medications for PD

- Pain Med: most are safe to use, but narcotic medications may cause confusion, psychosis and constipation.
  - If patient is taking MAOB inhibitor such as selegiline or rasagiline (Azilect®), avoid metoprolone (Demerol®).

Care Transitions from the hospital

Discharge to home or rehab facility.
- Be sure patient/family understands reviews usual med dosing and schedule with Rehab center team.
- Often errors occur when changes in usual medications schedules or dosages occurred during hospitalization (good or otherwise) then transferred (incorrectly) to rehab setting.
- If medications or schedules were changed during hospitalization a follow-up with the Neurologist is recommended.

Recommendations from the NPF Work Group

- 24,929 cases - 13489 had neurologist care
- 9112 PD-related hospitalizations
- Hospitalization occurred and recurred less often among neurologist-treated patients.
- Neurology treated patients had lower adjusted odds of both initial and repeat hospitalization for psychosis, UTI and traumatic injury.
- This may reflect an improved ability of neurologists to prevent, recognize, or treat PD complication.
Changes in Sleep

Difficulty with sleep maintenance
• Fragmented sleep. Numerous nighttime awakenings may progress with increase in motor symptoms

Causes
• Physical symptoms of Parkinson’s
  • Wearing off in middle of night
  • Nocturia
  • Obstructive Sleep Apnea (OSA)
• Emotional-mood disturbances
• Depression or anxiety
• Other
  • Naps during day
  • Presence of dreaming / REM Sleep Behavioral Disorder

RBD = REM Sleep Behavioral Disorder

The violent acting out of dreams = RBD.
When non PD persons dream their brainstem paralyses the body. But in PD this does not happen and during REM sleep the body still can move allowing acting out of dreams.
Safety issues for bed partner due to pt’s unconscious aggressive behavior – may hit the partner, jump out of bed, fall, yell, etc., can be a safety risk to patient and partner. (Attorney story)
First advise bed partner to sleep in different bed.
May need sleep study to check for OSA

Sleep Treatment Strategies

• RBD medications
  – 0.5-1mg clonazepam qhs
  – 6mg Melatonin
  – Sleep study with possible need for cpap (OSA)
• Sleep maintenance:
  – Treat for depression as indicated
  – Sleep medications
• Sleep hygiene measures
  – Limit daytime naps
  – Create a restful night-time environment and practice relaxation strategies

Story: Former military special forces & what he did to wife during sleep.

Parkinson’s Disease Sleep Scale

• Subjective report
• Validated for PD
• Will help determine best treatment options
  • Medications
  • Referral to team
  • Referral for sleep study
• Need permission to use

Autonomic Changes

Potential ANS Conditions

• Orthostatic or postural hypotension
• GI dysfunction
• Urinary urgency and frequency
• Changes in Skin
• Sexual dysfunction

Orthostatic hypotension

• Drop in BP with position change of 20 mm hg or more upon standing
• Occurs in 20-50%
  – not all are symptomatic of BP drop
• Causes
  • ANS dysregulation related to PD
  • PD medication may magnify problem
    – Results in PD med dosing limitations
• Symptoms
  – Lightheadedness, dizziness, unsteadiness, vision changes, impaired thinking (cognitive slowness), lethargy, fatigue, weakness, headache, neck tightness
Orthostatic hypotension management

- Medication evaluation/change
- Avoid rapid changes of position or straining
- Initiate ambulation slowly
- Increase fluids (work toward 8 cups/day)
- Increase salt intake, unless contraindicated
- Small frequent meals
- Raise head of the bed 30-40 degrees
- Compression stockings
- Medications to compensate (fludrocortisone, midodrine)
- Mestinon may help to prevent supine highs *


GI Dysfunction

- Excess saliva
- Dysphagia
- Nausea / gastroparesis
- Bowel dysfunction
  - Decreased frequency
  - Difficult bowel movements

Drooling

Noted in 70-78% in persons with PD
- Saliva production unchanged
- Loss of automatic swallow reflex
- Accentuated by:
  - Stooped posture
  - Open mouth
  - Socially isolating


Drooling Management

Treatments options include:
- Botulinum (Botox®) injections into the parotid and submandibular glands (effect lasts several months)
- Saltropine or other anticholinergic medication
- Cautious use of atropine® eye drops under the tongue (not to exceed 1-2 drops daily - can cause confusion)
- Papaya tablets
  - Meat tenderizer contains papaya as a main ingredient... small amount on a q-tip under the tongue
- Gum or hard candy may facilitate swallow
- Lemon juice and soda water

Importance of good oral care

Gastroparesis

Impaired or slowed stomach emptying

Cause:
- PD
- PD medication side effect
- Decrease in activity
- Decrease in fluid intake

Symptoms may include:
- Early satiety
- Sense of bloating
- Nausea and vomiting
- Weight loss

May hamper levodopa effectiveness

Constipation

- Fewer than 3 bowel movements per week
- Experienced by 29% of persons with PD
- Due to slowed passage through the colon
- Normal colon transit time about 24 hours
- Colon transit time ay be prolonged to 44 hours in PD
  - Has not been extensively studied
Constipation Management

- Increase fiber and fluids
- Prunes, prune juice, yogurt
- Increase physical activity
- Regular use of miralax®, stool softeners, senna
- Avoid bulk laxatives if decreased fluid intake

Cognitive Decline

Changes in thought, behavior and judgment. These changes can cause some of the most troubling and disabling symptoms in PD.

Attention
- Difficulty maintaining attention, easily distracted

Speed of information processing
- Slow sluggish thinking with a delay in verbal response

Working Memory
- Delayed retrieval of information and word finding

Executive function
- Difficulty with organizing, generating, shifting and blending different types of information “I can no longer multi-tasks”

Visuospatial changes
- Difficulty processing information about their environment

Changes in Judgment

- Driving
- Being left alone
- Kitchen safety
- Using appliances
- Using power tools

Screening Tool for Cognitive Impairment

Montreal Cognitive Assessment (MoCA)
- 1 page, 30 point test, Assesses 5 domains: visuospatial, language, executive function, attention concentration and working memory, and orientation
- Normal is 26/30
- Available in multiple languages on-line
- www.mocatest.org

Mini-Mental Status Exam (MMSE) - no longer recommended
- Can be normal and still have cognitive deficits.
- “People with PD and normal MMSE have broad range of cognitive performance.” (Burdict et al. 2014 Movement Disorders)

Cognitive Decline Treatment

- Acetyl cholinesterase inhibitors – Aricept®, Exelon®, Namenda®
- Cognitive stimulation “Use it or lose it”
- Cognitive retraining/memory strategies
- Focus on strengths
- Provide more direction
- Assure safety

Evaluating Cognition

- May need referral to Neuropsychologist to evaluate
- Consider if patient’s medications are at end of dose. Thinking is often better when medication is at peak dose.
- Think about the fatigue factor
- Reduce distractions in the environment.
- Give time to respond
- Make only one request at a time
- Don’t shift quickly between tasks or requests
- Referral to ST and OT

May be difficult for families to acknowledge and accept
Fatigue in Parkinson’s

- Associated with increasing Hoehn and Yahr stages
- Fatigue should be considered as a separate PD entity
- May be related to neuroinflammatory mechanisms
- 16 item Parkinson’s Fatigue Scale strongly correlated to the Fatigue Severity Scale **
- Consider methylphenadate (Ritalin®, Concerta®)
- Consider amantadine or eldepryl
- Referral to OT for energy conservation techniques

Complexities of Management

Motor vs. Non motor symptoms
- Non-motor symptoms include changes in mood, cognition, autonomic nervous system dysfunction, sleep, pain—they are often poorly recognized and inadequately treated (in contrast to motor symptoms)
- Non-motor symptoms often more bothersome to patient and family
- Non-motor symptoms can be improved with currently available treatments
  - Further research into more effective drug therapies are needed
- In 2010, the American Academy of Neurology (AAN) published Parkinson disease quality measures for standardization of treatment

Specific AAN Guidelines

- Erectile dysfunction—Sildenafil citrae (Viagra®) (but Cialis is better as it helps urinary urgency)
- Excessive daytime sleepiness—modafinil (Provigil®)
- Constipation- polyethylene glycol (Miralax®)
- Periodic limb movements of sleep (carbidopa/levodopa)
- Fatigue- methylphenadate (Ritalin®, Concerta®)
- Insufficient evidence for treatment of:
  - Orthostatic hypotension
  - Urinary incontinence
  - REM sleep disorder
  - Anxiety

Hallucinations and Delusions

Hallucinations - a phenomenon in which a person perceives that they see, hear, or feel something that is not physically present
- Visual hallucinations are most common
- Occurs in 50% *
- Specifically ask the patient and carepartner if they experience hallucinations
- VH with insight vs without insight. Most common reason for placement in SNF

Delusions - persistent, illogical beliefs or perception
- often paranoid in nature
- May be treatment related
- May be seen later in the disease process, thought to be a part of the disease pathology

Hallucinations and Delusions Treatment

- Discontinue agonist or amantadine
- If unable to decrease the levodopa dose, it may be add an atypical antipsychotic medication such as quetiapine
- Clozapine is most effective but requires blood monitoring- danger of agranulocytosis (lowering of the white blood count)

Caring for the Caregiver

Transitions in Mid-Stage PD
In Mid-stage the care partner may begin to feel more like a caregiver
- Multiple aspects of care giving
- Physically more difficulties
- Emotionally difficult
- Reduced daily skills such as driving, paying bills
- Affects health and quality of life of the care giver
- Person with PD may be a different person since becoming ill
- Verify care partner referred to a support group
Evaluating Caregiver Strain

- Multidimensional Caregiver Strain Index (MCSI)
- Validated measure of caregiver burden and strain (Stull 1996)
- Modified for use in PD (Carter et al. 1998)
  - Identifies whether the external criteria, some of which could be considered causes of caregiver strain
  - Others consequences of strain are differentially related to dimensions of caregiver strain.

Nursing Interventions

PATIENT EDUCATION
- Provide National Parkinson Foundation (NPF) brochures and booklets and other appropriate reading materials to patients and caregivers www.parkinson.org
- Discuss support groups opportunities with patient and caregivers, and encourage participation if they have not yet tried attending one