Session Objectives

• Describe nursing roles in the care of PD patients
• Describe evidence-based nursing practice
• Describe nursing assessment across the continuum of care with the focus on early stage PD
• Describe nursing interventions across the continuum of care with the focus on early stage PD
• Describe at least two tools used for assessment of depression in Parkinson disease
### Receiving a Parkinson’s Diagnosis

Key factors affecting the individual’s QOL and how the news was delivered:

- Depended on their current level of optimism
- 50% of the people were depressed, but only 1% reported it as a problem
- Myth: “I wouldn’t be depressed if I didn’t have PD” – not necessarily true! (See prodromal sx’s)

*Global Parkinson’s Disease Survey Steering Committee, Mov Disord 2002;17:60-7*

### Receiving Bad News-patient perspective

- Highest degree of satisfaction was correlated with:
  - Quality of information
  - Emotional supportiveness

- Low emotional supportiveness could not be fully compensated by high quality of information and visa-versa


### Receiving a PD Diagnosis

- Parkinson’s is an unpredictable disease with unique individual symptoms and progression
- Uncertainty and unpredictability create anxiety in the patient, care partner and family
- Modifiers which affect individual response:
  - severity of observable symptoms
  - stage of life (younger vs. older)
  - acceptance by others (spouses, friends, work & community)

### 6 Steps for delivering Bad News

- **Fire the ‘warning shot’** - “I’ve got some news” (setting up discussion)
- **“What do you know already?”** (assess perception)
- **“What and how much do you want to know?”** (Assess their needs/goals)
- **Tell them the news, and pause for their response.**
- **Respond to their feelings/empathize.**
  - “I wish that things were different.”
- **Plan for next step(s), strategies and recommendations**

*– Buchmann (2000); Shin & Casarett (2011)*

### Receiving the Diagnosis

Frequent questions asked:

- What is Parkinson and how did I get it?
- Is it hereditary?
- Will I be able to continue working? Do I tell my employer?
- Will I be able to support my family?
- What can I expect?
- How long before I am dependent on others?
- What are my treatment options?
- How will this affect my relationships?
- Will I die from Parkinson’s Disease? When?

### Caregiver Strain: Young vs. Older


- Even when care needs were few, younger spouses (40-55) experienced higher strain (‘worry’, global strain, lack of financial resources) and overall a lower sense of lack of “meaning” from caregiving.
- Older spouses (70+) had longer duration of relationship, were less concerned about resources, and had greater sense of “meaning” for caregiving.
- Prior to dx, the relationship quality predict caregiver depression and coping.
**Role of the Nurse with Newly Diagnosed**

- Determine the patient’s/families’ knowledge and perception, proceed at their pace, take time to listen and observe
- Communicate clearly
  - Try to offer the “right information at the right time”
  - Avoid medical jargon but educate them on ‘language’
- Refer couples for counseling or support groups
- Offer contact information for exercise and wellness programs.


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**Young Onset Parkinson’s**

- Diagnosed during the most productive years of their lives
- Live longer with the disease
- Increased risk for non-motor PD features

**Issues to address:**
- Motor symptoms: Medication management
- Non motor symptoms: Anxiety, depression, sleep, pain
- Family, financial support, relationship changes, employment

**Support options:**
- Young Onset Support groups
- On-line chat forums
- Annual Young onset conference

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**Access Resources and Plan for the Future**

“*Parkinson 101*” classes

- Provides interaction within same stage or age group
- May be more appealing than a support group meeting

If classes or support not available in geographic area:
- Booklet/video available from Parkinson’s Disease Foundation
- Diagnosis Parkinson’s Disease: You are not alone
- Addresses questions that may arise upon diagnosis, shares resources, medical expert testimony and the experience of people who have dealt with a diagnosis of PD

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**Establish A Relationship**

Focus on education for empowerment
- World PD Congress: 2016 in Portland
- Local PD educational classes, support groups
- Online resources
- Warnings about ‘magical cures’
- Medication education (language On’s/Offs; ICD’s)
- Benefit of exercise/rehab (recumbent bicycle Tai Chi, tango dance, yoga & other modes of exercise)
- Teach about recognizing their non-motor symptoms (anxiety, pain)
- Nutrition (holy grail, little research)
- Offer a positive and hopeful spirit, research studies (MJ Fox Foundation)

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**Develop ‘new diagnosis’ program**

- Ex: Struther’s “Finding Options for Care, Understanding, and Support” allows individuals to tailor the program to their unique needs and concerns.

- **FOCUS components include:**
  - Quarterly PD 101 classes
  - Monthly education and support classes
  - Opportunity to request written materials regarding non-pharmacological concerns
  - Personal contact through 3 phone calls within the year-long program

The FOCUS program was made possible through a grant from the National Parkinson Foundation

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**PD: “Head-to-toe” Symptoms**

- **Autonomic/Enteric Nerv System:**
  - GI: bloating, satiety, vomiting
  - GU: OAB, UI
  - CV: OH/LH, dec HR variability
  - Drooling, rhinorrhea, sweat

- **Sleep:**
  - RBD, RLS, OSA, EDS, fatigue
  - Insomnia, hypersomnia, sleep fragmentation, sleep terrors, nightmares

- **Sensory:**
  - Under-recognized, diverse, vague
  - Olfaction (premotor)
  - Pain
  - Tingling, burning, sharp, aching, no neuroanatomic pattern
  - Cognitive/Behavioral...
Challenges associated with PD

Hoehn and Yahr Staging

- **Stage I:** Unilateral involvement (can last 1-5 yrs)
- **Stage II:** Bilateral or Axial involvement without balance impairment (4-7 yrs)
- **Stage III:** Bilateral involvement (5-10 yrs)
  - Mild postural imbalance
  - Patient leads independent life
- **Stage IV:** Bilateral involvement (10-15 yrs)
  - Postural instability
  - Patient requires help with activities of daily living
- **Stage V:** Fully developed disease (17-20+ yrs)
  - Patient restricted to bed or chair

Transitions

Multiple transitions occur throughout the journey of living with Parkinson’s (average is a yearly progression)

- **Story:** “See this slow moving bus coming at you…”
  - **Usually the early stages of disease = ‘honeymoon’**
    - **Story:** “When the medications worked miracles”
  - The individual with PD may have different concerns than their care partner (partner, adult child, friend)
    - Important to consider both individual and family needs, and how they intersect
  - **Nursing plays a key role to develop a therapeutic relationship with the pt/family and liaisons with the team** Story: Bill won’t let wife help him….

Assessment Tools-UPDRS

**UPDRS-Unified Parkinson’s Disease Rating Scale**

- I (1-2) Mentation, Behavior and Mood (0-16)
- II (5-17) Activities of Daily Living (0-52)
- III (18-31) Motor (0-108)
- IV (32-42) Complications of treatment

- Most items rated 0-4, some 0/1
- Total score 0-100
- Sitting and standing blood pressure, heart rate, and weight

The multi-visit format allows comparison visit to visit, providing an excellent educational tool

UPDRS Multi-visit form

Evaluating quality of life

- Successful management must extend beyond diagnosis and disease treatment and include promotion of function and minimizing decline
- Need to evaluate/consider Health Related Quality of Life (HRQOL) **
  - Measures health beyond a deficit perspective to include physical, mental and social domain
- In PD, medical and surgical interventions modify motor symptoms of PD
- Large impact on overall quality of life are non-motor symptoms
  - Mood, cognition, sleep, fatigue, pain, decreased social interaction, role alteration

Assessment Tools

- Quality of Life---PDQ-39, PDQ-8
- Evaluates 8 domains, 0-4 scale, never to always
  - Mobility
  - Activities of daily living
  - Emotional
  - Stigma
  - Social support
  - Cognition
  - Communication
  - Bodily discomfort
Assessment Tools: UPDRS and PDQ-39

- Worsening UPDRS II scores (ADL) correlate with low quality of life
  - Shows importance of measures of independence as a determinant of quality of life for an individual
  - Quality of life in patients with PD is strongly influenced by disease severity and functional status*


Education-Health Maintenance

Parkinson’s and bone health

- Increased risk for fractures, especially of the hip due to increase risk of falls
- Bone mineral density is generally lower in individuals with PD compared to age/sex matched controls (high turnover osteoporosis)
- Recommendation: newly diagnosed patients should be evaluated for risk of falls and osteoporosis (Dexa Scan) and supplemented with vitamin D with Ca++
- Barriers: Insurance coverage


Develop effective strategies for staying healthy

Parkinson’s disease and melanoma

- Renewed interest in melanoma and PD during rasagiline studies with report of association of skin cancer and PD
- 2010 Mov disorders-review of 26 studies
  - Higher frequency of melanoma
  - Recommendation: early diagnosis through annual dermatology checks

Pan T, Jankovic J, the association between Parkinson’s disease and melanoma, International Journal of Cancer 2011 Jan 4

Develop effective strategies for staying healthy

Nutrition

- Most nutritional studies in PD have shown conflicting results *
  - Many focus on single nutrients rather than dietary patterns
- Largest prospective study of dietary patterns showed a Mediterranean-type diet protective for PD in both males and females**
- Adherence to a Mediterranean-type diet may affect the risk of AD, but also pre-dementia syndromes (MCI) and their progression to overt dementia.***


Nutrition-the Mediterranean Diet

- High intake of fruit, vegetables, legumes, whole grains, nuts, fish, poultry may protect against PD
- Elevated saturated fats could have a negative effect on cognitive decline

Develop effective strategies for staying healthy

Nutrition-Omega 3 fatty acids:
- A group of essential fatty acids that play crucial roles in the maintenance of normal neurological function
- Neuroprotective properties and beneficial effects on the cognitive functioning with aging.
  - Growing evidence that cognitive functioning of the aging brain can be preserved, or loss of function can be diminished with omega-3 fatty acids


Fish oil has a high content of omega-3 fatty acids
- Provides the natural form of DHA and EPA that does not need to be converted in the body (plant forms such as flaxseed need conversion of DHA and EPA in the body)
- May decrease inflammation, improve the immune system, lower blood triglyceride levels, and reduce the formation of blood clots
  - Do not take with blood thinners
  - Discuss with your clinician prior to starting, esp. if take aspirin or NSAIDS


Effective strategies for staying healthy

Complementary Therapies
- Massage
- Tai chi
- Horticulture
- Aromatherapy
- Creative activities
- Spiritual care
- Yoga
- And many more!

Address Common PD Problems

Depression in PD
- 40% prevalence (range 3%-90%)
- Clinically significant in 35%
- It is under-recognized, under-diagnosed and under-treated
- A non-motor sx of PD, may pre-date dx
- Suicide ideation should be assessed - “do you have a plan?”
- The impact of depression extends to family and carepartner burden
- Care partners may identify pt has a disinterest in people, sex, or normal outside activities
### Depression in PD

**Overlap of Depression and Parkinson’s Symptoms**

<table>
<thead>
<tr>
<th>PD</th>
<th>Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>Loss of facial expression</td>
<td>Loss of facial expression</td>
</tr>
<tr>
<td>Psychological and motor slowness</td>
<td>Psychological and motor slowness</td>
</tr>
<tr>
<td>Sleep Fragmentation</td>
<td>Sleep disturbance</td>
</tr>
<tr>
<td>Fatigue</td>
<td>Fatigue</td>
</tr>
<tr>
<td>Decreased interest in activities</td>
<td>Decreased interest in activities</td>
</tr>
<tr>
<td>Decreased attention</td>
<td>Decreased attention</td>
</tr>
<tr>
<td>Loss of appetite</td>
<td>Loss of appetite</td>
</tr>
</tbody>
</table>

### Depression Screening Tools

- Beck Depression Inventory (BDI)
- Geriatric Depression Inventory (GDS)
- Hamilton Depression Scale (Ham-D)
- If depression is suspected, helps patients accept treatment when explained it is part of the disease process, lack of neurotransmitters

Schrag, A, Barone, P Depression rating scales in Parkinson’s disease: critique and recommendations, Mov Disord, 2007 Jun 15;22(8): 1077-92

### Anxiety in Parkinson’s

- Common non-motor sx
- No correlation to disease severity or degree of disability. May be disproportionate to the PD symptoms, and is often not well controlled
  - May accompany depression
  - Will make all PD symptoms worse
  - May be linked to the on/off phenomenon

**Example:**


### Symptoms of Anxiety

- Generalized anxiety is a feeling of fear and uncontrollable worrying
- 25-45% experience some form of anxiety
- Patient feels out of control
- Panic attacks are common: May experience physical symptoms such as sweating, heart-racing, difficulty breathing, increased tremors or “butterflies in their stomach”
  - May be chronic or episodic
  - Range from mild to disabling
  - May result in trips to the ER
  - Anxiety can spill over to caregivers, causing them great distress

### Treatment Depression and Anxiety

**Antidepressants**

- **SSRI’s**: Selective serotonin reuptake inhibitors
  - citalopram (Celexa), escitalopram (Lexapro), fluoxetine (Prozac), sertraline (Zoloft), paroxetine (Paxil)
  - SNRI’s: Serotonin, norepinephrine reuptake inhibitors
  - venlafaxine (Effexor, Effexor XR), duloxetine (Cymbalta), desvenlafaxine (Pristiq)
  - Atypical antidepressants
  - mirtazepine (Remeron), bupropion (wellbutrin IR, SR), Desyrel (Trazodone)
  - Tricyclic antidepressants
  - Side effects in elderly: memory, confusion, sedation

### Treatment of refractory Anxiety

**Anti-anxiety treatment**

- SSRI’s and SNRI’s AND if needed, PRN
- Benzodiazepines
  - Diazepam, Alprazolam
  - Side effects: memory, confusion, drowsiness, balance problems, tolerance
- Assess if correlated with wearing off adjustment in PD medications may be helpful
  - Story: Mr. Golfer unaware of wearing off’s anxiety, sense of doom
- Nurses can help patients distinguish between anxiety, worsening symptoms and the “off” state
**Non-drug approaches**

Non-drug approaches for treatment of depression and anxiety

- Relaxation techniques through visualization, music, biofeedback (Mindfulness Courses)
- **Parkinson’s Outcomes Project - NPF**
  - Depression is best treated when referral is made to Social Worker or counselor
- Therapeutic creativity
- Exercise
- Omega 3 fatty acid supplementation?

31 patients with PD and Major depression (DSM-IV)
PD patients taking fish oil supplements, with or without antidepressants, showed improvement in depressive symptoms

De Silva TM, Munhoz et al., Depression in Parkinson’s disease: A double-blind, randomized, placebo-controlled pilot study of omega-3 fatty acid supplementation. J Affect Disord, 2008 May 14

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**Early-stage: Cognitive Changes**

- Bradyphrenia and loss of executive functioning (slowed responses, can't keep up, can no longer multi-task)
- Stern and Siderowf (2010) - PARS study
  - Pre-motor cognitive changes
  - Short Term Memory decline
- Fatigue
- Daytime sleepiness
- Insomnia (trouble staying Asleep.)

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**Sexuality and PD - Needs Creativity**

Diagnosis of PD may alter self-perception as a sexual being

Awareness of altered physical appearance
- Rigidity and bradykinesia may inhibit bed mobility
- May be self-conscious of excessive salivation or sweating
- Difficulty in expressing emotions or facial masking may cause misinterpretation of feelings by the partner
- Fatigue or emotional symptoms of depression or anxiety may inhibit interest by the person living with PD
- Change in ability to achieve orgasm in both men and women add strain to a relationship
- May experience loss of spontaneity due to need for timing of PD medications for best functioning

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**Communicate Better**

- **Family involvement:** Family often less involved when symptoms are more mild or are well controlled
- Backer’s study--70 men and women, aged 44-80
  - Stressors resulted in >50% increase in symptom severity during times of stress
  - If pts perceived less family support → more evasive coping behaviors → greater health dysfunction
  - Families need to understand the impact of fatigue, depression, and/or anxiety’s impact on relationships and daily life
  - With awareness of what to observe for, they become proficient at monitoring and reporting as part of the team


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**PD Med Management**

- Medication selection is individual, dependent on:
  - Age
  - Symptoms
  - Co-morbidities
- May begin treatment with:
  - No medication (previous controversy about when to start levodopa)
  - Dopamine agonist (mirapex, requip)
  - Levodopa (combined with carbidopa)
  - Other agents such as amantadine or (Azilect) MAO-B inhibitor
Medications

<table>
<thead>
<tr>
<th>Dopaaminergic agents</th>
<th>Anticholinergic agents</th>
<th>Antiviral agents</th>
<th>Medications for Dyskinesias</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carbidopa/levodopa, carbidopa/levodopa CR, Parcopa®</td>
<td>Trihexyphenidyl</td>
<td>Amantadine</td>
<td>Apokyn®</td>
</tr>
<tr>
<td>Dopamine Agonists (Requip®(IR and ER), Mirapex®(IR and ER), Neupro patch®)</td>
<td>Benztropine</td>
<td>Zelapar®</td>
<td>Endoprazine</td>
</tr>
<tr>
<td>COMT inhibitors (Comtan®, Stalevo®, Tasmar®)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MAO-B inhibitors (selegiline, Zelapar®, Azilect®)</td>
<td>Apokyn®</td>
<td>Bupropion</td>
<td>Azilect®</td>
</tr>
</tbody>
</table>

Other Frequently Used Medications

- Anti-depressants and anti-anxiety agents
- Cognition and memory medications (aricept)
- Atypical anti-psychotics (Seroquel)
- Autonomic Nervous System Dysfunction meds (midodrine)

Initiating Medications

Provide education regarding:

- Expected medication effects
  - Effect of medication on symptoms
  - Importance of taking pills on time according to prescribed schedule
- Potential effect of protein and levodopa (may instruct to take with food at the start of treatment)
- Potential medication interactions for MAO-B medications
  - Important side effects (nausea, lightheadedness, ICD’s)
  - Timing of expected symptom benefit, which may take several weeks. The slow escalation is to ensure tolerance and reduce potential side effects

Medication follow-up

- Ask the patient what specifically has improved. Which symptoms are better.
- Patients may not recognize if they are better. Check with care partner as to their observations.
- Assess for unrealistic expectations.
- If patient has experienced side effects may lower or stop the medication, and observe for change in symptoms.
- Make only one change at a time so can determine what is making a difference.
- If need to discontinue a medication due to bothersome side effects - slow taper usually recommended.

Follow-up/on-going care

Clinical Interview

- List patient’s top 3 concerns (current bothersome symptoms)
- Current PD meds and schedule (include time of day taken)
- Illness or surgery since last appointment
- Assessment of secondary symptoms (cognition, mood, ANS)
- ADL’s - Triage for referral to rehab therapies (UPDRS ADL comparison helpful)
- Triage for support services/resources/carepartner needs
Putting It All Together
Discuss and review the After Visit Summary
- Changed & continued medications, (what specifically changed)
- Medication Diary if complicated schedule
  - Listing of all meds with recommended times
- Develop written materials or use PDF, NPF or APDA published handouts
- Confirm/coordinate referrals to the Rehab team, Speech therapist, Social Worker or research staff
- How they can contact your clinic and when to report problems or successes

Patient/Client/Family Education
Research validates that 40-80% of care instructions received are forgotten almost immediately

Confirm Patient Understanding
“Tell Back” works best to confirm patient understanding
- Patients often leave medical encounters with poor understanding of their health conditions and recommended treatment
- 2008 study in J Am Board of Family Medicine, tested 3 types of inquiry about patient’s understanding
  - Yes-No
    - “I’ve given you a lot of information. Do you understand?”
  - Tell back-Directive
    - It’s really important that you do this exactly the way I explained. What do you understand?”
  - Tell-back Collaborative
    - I know you want to function better during the day. I’ve given you a lot of information. It would be helpful to me to hear your understanding about your medication schedule.”

How?
Use open ended questions
- “Tell me in your own words about …?”
- “Explain to me what the clinician or care team informed you about.... “
- “Show/demonstrate how you would...”
- “What symptoms would cause you to see your doctor?”

“The journey of a thousand miles begins with a single step”
Ancient Chinese Proverb