Psychosocial Factors in Parkinson’s Disease

Kimberly Lanni, Ph.D.

Clinical Neuropsychologist

Valley Psychological Center

Roseville, CA
Psychosocial Factors in PD

• *Aim:* To increase understanding of the non-motor, psychosocial aspects of PD on patients and their caregivers.
Introduction

• Medical Treatment for PD is often aimed towards alleviating the cardinal motor symptoms (resting tremor, rigidity, bradykinesia, postural instability)
  – Symptom Management, Medication Adjustment

• Attention to the interactive effects of the biomedical, psychological, and social dimensions of disease improves patient care (Dr. George Engel; *Science*, 1977)
Non-Motor Symptoms

- Less visible changes experienced by PD patients may have a dramatic effect on psychological well-being, social adjustment, and quality of life for both patients and caregivers
  - Depression, Anxiety, Psychosis, Sleep Disturbance, Loss of Income, Communication Difficulties, Social Isolation, Driving
Patient-based Needs Assessment

- Kleiner-Fisman, Gyrfe & Naglie (2013) recently performed a patient-based needs assessment using focus groups of PD patients, asking:

  "What information is missing from your healthcare experience or has been missing in the past that would help you live well with PD?"
Patient-based Needs Assessment

- Of the content areas identified, patients ranked Emotional coping, Relationships, and Social Aspects as the area of interest having the greatest impact on health and functioning (Figure 1)
  - Dealing with fear about the future
  - Coping Strategies
  - Coming to terms with living with a chronic illness
  - Challenges for marital relationship (including helping the unaffected spouse/caregiver come to terms with living with a chronically ill individual)
  - Availability of programs that promote a sense of wellbeing in dealing with disease
Patient-based Needs Assessment

Figure 1: Summary scores for informational categories identified by patients as missing from their care. Raw scores are plotted on the left Y-axis; rescaled (0–100 scale) are plotted on the right Y-axis. Kleiner-Fisman, Gyrfe & Naglie (2013)
Role of MH Providers

- MH Professionals may play a key role in assisting with psychological and social implications of PD
- Early involvement of MH Professionals as a member of the interdisciplinary treatment team may be critical in minimizing the impact of PD on quality of life (Ellgring et al., 1993; Macht, Schwarz & Ellgring, 2005)
Psychosocial Adjustment to PD

• Adjustment to chronic, progressive illness
  • Uncertainty prior to diagnosis; Relief upon learning explanation of symptoms/learning about treatment; Patient and family assimilate to PD as one aspect of life without it becoming focal point of identity and interactions

• Assimilation to PD is not without complexity
  • Period of Grieving
  • Sense of loss, rate of progression, & presence of dyskinesias, negatively effect quality of life (Jahanshahi, 2003; Marras et al., 2004; Playfer, 2002)
Assimilation to PD

- Changes in family/social roles, reduced independence, fatigue, pain, unpredictability, and a new sense of identity (Habermann, 1996; Herlofson & Larsen, 2003)
Assimilation to PD

- Factors associated with patient well-being and caregiver outcomes
  - Sense of Meaning in Life, Personality, and Social Connectedness (Nelson et al., 2003; Schrag et al., 2003)
  - Social Support (Symister & Friend, 2003)
  - Optimistic Attitude (Lyons et al., 2004)
  - Perceived control over disease progression (Wallhagen & Brod, 1997)

- MH Intervention: Aimed to promote these qualities
Common Psychological and Social Challenges

• According to several surveys, depression and other psychiatric symptoms have greater impact on quality of life than motor symptoms (Global Parkinson’s Disease Survey. Mov Disord 2002; 17:60-67)
  – Not just for the patient, but loved ones as well
  – Depression, behavioral, and cognitive symptoms increase caregiver strain more than physical symptoms (Aarsland et al, 1999; Carter, et al., 2002; Schrag et al, 2006)
Depression

- Prevalence of depression varies from 25-40%, can occur at any stage of the disease, and may even occur prior to the onset of motor symptoms (Cummings, 1992; Doonreief et al., 1992; Yamamoto, 2001)
Depression

• Initial Intervention: Monitoring for symptoms by patient, caregiver, and providers
  – Fatigue, apathy, psychomotor retardation, poor motivation, sleep disturbance, anorexia, suicidal ideation
    • Important: disease progression and “wearing off” can mimic depression (e.g., anxiety, sense of impending doom, dysphoria) – so ask if there is pattern of symptom onset
    • “On-Off” Fluctuation (increased symptoms when “off” while mood improves “on”)
Depression

- Intervention: Pharmacologic and/or Nonpharmacologic
  - Nonpharmacologic: good nutrition, sleep hygiene, moderate cardiovascular exercise, PD support group, social interaction, stimulating leisure activities
  - Psychotherapy (individuals and couples): CBT has been proven effective in treating depression in PD (Cole & Vaughan, 2005; Dobkin, Allen, & Menza, 2006)
Anxiety

- Prevalence: up to 40% (Richard & Kurlan, 2008)
  - Can manifest through somatic complaints, restlessness, irritability, and muscle tension (Marinus et al., 2002)
  - Motor symptoms, balance and gait disturbance, freezing episodes, increased fall risk can contribute to anxiety (Fitzsimmons & Bunting, 1993)
Hallucinations

- Hallucinations are typically secondary to dopaminergic therapy, 20% experience at some point
  - Risk factors: cognitive dysfunction, older age, history of depression, sleep disorder
  - Often occur at night and are almost exclusively visual
    - Typically people, animals, insects
Impulse-Control Disorder

• Impulse-Control: excessive dopaminergic stimulation (prevalence approximately 6%: Voon, et al., 2006)
  – Gambling, compulsive shopping, hypersexuality, hobbyism, punding (excessive, repetitive, purposeless bx: shuffling papers; reordering bricks, sorting handbags), compulsive medication use (in excess of dose required to alleviate motor symptoms)
  • Distressing to patient and can be devastating to families
Communication

• Nonverbal Communication – overlooked because caregivers concerned with the motor aspects of disease (Pell & Monetta, 2008)
  – Social Pragmatics and Language Processing (e.g., joke versus lie) (Monetta, Grindrod, & Pell, 2009)
  – Restricted Facial Expressions and Body Posture
  – Decreased emotion recognition (e.g., face depicting anger; surprise)
    • leads to interpersonal difficulties including, frustration, isolation, social discomfort, and difficulty with connectedness (Clark et al, 2008)
  – Changes in Articulation; Voice Quality and Modulating Pitch & Volume
  – **To Cope:** Use Direct Communication – Less Reliance on Social Cues
Social Isolation

- Can occur due to decreased mobility, fatigue, pain, depression, embarrassment re: symptoms, & communication difficulties
- Interventions:
  - Exercise program – improved social interactions (de Paula, et al., 2006)
  - Volunteer activities, Support groups, Leisure activities
Interpersonal Effects

Altogether, psychiatric symptoms and declines in emotion recognition, social pragmatics, and nonverbal communication abilities can be highly distressing and have profound effects on the interpersonal relationships between individuals with PD and their loved ones.
Pre-Post DBS

- 12 months post-STN DBS, Physical aspects of patient-reported quality of life (PDQ-39) significantly improved, as did clinician ratings (UPDRS parts II and III) (Drapier et al., 2005)

- Emotional/Behavioral aspects of QoL showed no improvement (PDQ-39)
  - Including Communication, Emotional Well-being, Social Support, Cognition
Pre-Post DBS: Perceived Outcome

- Apathy, anxiety, and suicidal ideation increased significantly in some patients, post-DBS, despite stable depressive symptoms (Drapier et al., 2005)
- Preoperative behavioral symptoms and shorter disease duration were determined risk factors (Porat, Cohen, Schwartz, and Hassin-Baer, 2009)
  - Rigorous selection recommended, including absence of premorbid personality disorder (Houeto et al., 2006)
Pre-Post DBS: Perceived Outcome

- Despite decreased motor disability, difficulties with cognition, self-perception, spouses, families, and professional environment persisted (Schupbach et al., 2006)
  - Marital Conflicts in 17/24 couples
  - Only 9/16 patients went back to work
Pre-Post DBS: Perceived Outcome

• Overestimation of Performance: Increased risk-seeking behavior in conjunction with poor performance in post-operative DBS group (Florin et al., 2013)
  – Potential impacts professionally as well as within interpersonal relationships
Pre-Post DBS: Perceived Outcome

- Stress in the Marital relationship (Bell, et al., 2011)
  - Scenario 1: Spouse disappointed by reclaimed independence (e.g., independently driving to visit friends)
  - Scenario 2: Spouse disappointed by continued degree of dependence (e.g., unmet need to remediate caregiving exhaustion)
Pre-Post DBS: Perceived Outcome

• Vocational
  – For some patients, DBS can improve work performance
    • Example: Writer whose typing speed hampered by motor symptoms
  – For others, can create new psychosocial challenges
    • Example: Regaining employability with the absence of work experience/training due to prior disability
Pre-Post DBS: Perceived Outcome

• When evaluating candidacy for DBS, social support is a critical factor in potential treatment success
  – Transportation to clinic for ongoing management
  – Recognition of cognitive/psychiatric side effects
    • Mood, impulse-control
• Importance of continuously integrating psychological care and psychosocial education with DBS programming (Cohen, Oh, Baser, et al., 2007)
Summary

- The non-motor, psychosocial symptoms associated with PD can be more distressing for patients and caregivers than the cardinal motor symptoms & persist post-DBS
Summary

- Comprehensive Assessment and Symptom Management includes:
  - **cardinal motor symptoms** (resting tremor, rigidity, bradykinesia, postural instability)
  - **cognitive symptoms** (mild cognitive impairment, dementia)
  - **psychiatric symptoms** (depression, anxiety, hallucinations, psychosis, impulse-control, sleep)
  - **psychosocial adjustment** (interpersonal relationships, social isolation, communication effectiveness, financial strain, involvement in community support groups, need for education, driving safety)
  - **caregiver stress**
Guidelines for Healthcare Professionals  (Nelson, 2008)

• Conduct regular interdisciplinary conferences involving the physician, psychologist, occupational therapist, physical therapist, speech-language pathologist, social worker, chaplain, and other team members

• Encourage the patient to follow medical recommendations, particularly as related to medication, exercise, and psychological support
Guidelines for Healthcare Professionals  (Nelson, 2008)

- Be alert to signs that patients and/or families are becoming overwhelmed, such as depression, isolation and fatigue
- Encourage participation in a support group that offers both education and social support
Guidelines for Healthcare Professionals (Nelson, 2008)

• Share information about adaptive equipment, community resources, and patient education materials

• Include family members or close friends in appointments, especially if you suspect changes in memory
Thank You