ALLIED TEAM TRAINING FOR PARKINSON

PSYCHOSOCIAL CHALLENGES IN MIDDLE STAGE PD

Elaine Book, M.S.W.

Learning Objectives

• Discuss common psycho-social challenges in the middle stage of PD for the person with Parkinson’s (PWP) and their caregiver
• Describe various causes of anxiety and impulse disorders in persons with PD and possible treatment
• Describe the impact of ambiguous loss and grief in PD
• Identify social work interventions for PWP and caregivers
Typical Changes in Middle Stage

• Disease progression is gradual
• Rate of progression varies in different patients
• Goal of treatment:
  • is not to abolish symptoms, but
  • to help PWP manage symptoms,
  • function independently and make appropriate adjustments

Di Minno and Aminoff, 2003

Typical Changes in Middle Stage

• Middle stage -- more unpredictability
• Makes it very difficult to plan anything with certainty
• This can cause much frustration to caregiver
Typical Changes in Middle Stage

- PWP may isolate due to depression, shame and apathy
- Feelings of shame, embarrassment over symptoms, particularly tremor, and humiliation can occur
- Heightened vulnerability, fear of losing control, anxiety with wearing off periods may be experienced

Di Minno & Aminoff, 2003

Typical Changes in Middle Stage

- PWP are often aware of the progressive nature of illness and it can become source of anxiety
- May over-monitor themselves,
- Compare themselves to others and
- Avoid situations like support groups where they see more advanced patients

Di Minno & Aminoff, 2003
Anxiety Disorders

- Panic attacks
- Generalized anxiety disorder
- Phobias:
  -- social phobia
- Prevalence: 25-40% in PWP
- May precede PD

Anxiety Disorders

Features:
  -- May be part of depressive symptoms
  -- Often episodic
  -- Can exacerbate motor symptoms
Symptoms often not recognized
Anxiety Disorders

• Anxiety fluctuates with “on-off” states

• Often, not always, PWP are more anxious during off periods

• Stress adds to anxiety states

Anxiety Disorders

• Studies suggest little relationship between severity of motor disability and severity of anxiety

• Anxiety typically managed with medications

• Cognitive-behavioral therapy may be helpful
Impulse Control Disorders

Impulsive Behaviors:
--pathological gambling
--hyper-sexuality
--pathological shopping
--disinhibition
--obsessive-compulsive behaviors

Impulse Control Disorders

Impulsive behaviors are being studied in the PD population
Possible causation:
• treatment induced stimulation of dopamine receptors
• a side effect of neurosurgical procedures (DBS)
### Impulse Control Disorders

- Treatment—usually reduction or withdrawal of anti-parkinsonian medication for hyper-sexuality or for pathological gambling
- Support and education for caregiver

### Impact on Family

- Bio-psycho-social issues
  - Motor and non-motor changes
  - Unpredictability, the on-off quality of the illness creates added stress
  - Number of direct care activities increase as PD progresses
### Impact on Family

- Increased levels of stress
- Worry
- Depression
- Anxiety

Carter, Stewart, Archbold, Inoue et al., 1998

### Impact on Family

- Tension and frustration from communication problems higher
- Worry, strain from direct care, role conflict, global strain increase
- Number of care activities increased
- Negative lifestyle increased
Impact on Family

- Depression for caregivers may increase
- 17.5% of caregivers in Carter’s study were in the depressed range

Impact on Family

- The average caregiver will be experiencing some strain and for some, considerable strain
- Psycho-educational interventions - effective in strain reduction in spouse caregivers
- Dementia of care receivers may be biggest factor in caregiver depression
Impact on Family

Couple Stress
- Sexual dysfunction is often an issue as the disease progresses
- Education is helpful
- Create a milieu where sexual issues and intimacy issues can be discussed in a “matter of fact” way
- Vulnerability for elder abuse

Impact on Family

Chronic losses
- Loss of role
- Financial security
- Dreams of the future
- Equal partnership, intimacy
- Reduced personal opportunities
- Pain of seeing their partner/family member decline and suffer
- Physical hardship, personal stress and physical decline

P. Boss, 1999
### Impact on Family

- Ambiguous loss:
- Frozen grief-difficult to mourn
- Physically present, psychologically absent (Alzheimer’s)
- Psychologically present, physically absent (MIA, Parkinson’s)

P. Boss, 1999

### Economic Repercussions

- Economic downturn
- Ability to purchase help affects everything
- Role reversals: patient may lose job, care partner may have to work longer hours
- Stress builds with economic distress
Family Focus

• Evaluate family in terms of life cycle stage and tasks
• Young-onset PD patients with families with children present important and different issues
• Evaluate couple system, parental system, role of the children in the family

Family Focus

• Hold family sessions with all members to discuss what is happening. Explore family secrets.
• In families where the PWP is older, it is common to conduct family sessions with the PWP, the care partner, adult children, siblings, and anyone involved in caregiving.
Family Focus

- Ask the PWP and the care partner who they consider “family”
- Gay and lesbian couples’ needs should be addressed
- PD impacts on everyone in the family system
- Consider the impact of culture

Interventions

- Encourage communication between couple and family members
- Engender problem solving as family
- Identify resources
- Encourage connection to others, counter isolation
- Talk about difficult topics: grief, losses, end of life issues
Interventions

• Parkinson’s disease gives time to the PWP and the care partner to talk before dementia and severe speech disability occur
• Differs from Alzheimer’s disease which often robs families of this option

Interventions

• Fear and anxiety could cause families to avoid open communication about difficult topics
• Social workers can help families communicate and stay connected
Resiliency

- Families/carepartner units often show resiliency
- The “we” quality of couples is important to assess
- Clinicians can build on these strengths when helping couples/families

Group Support

- Support group for persons with PD
- Support group for caregiver
- Joint groups: both PWP and caregiver
Group Support

- Education and process models

- Social group: often combines education with a social atmosphere. Open to anybody who wishes to attend. Can be PWP or care partners or both.

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