ALLIED TEAM TRAINING FOR PARKINSON

PSYCHOSOCIAL CHALLENGES IN EARLY STAGE PD

Elaine Book, M.S.W.

Learning Objectives

• Examine the role of social work in the provision of psycho-social treatment for individuals and families impacted by Parkinson’s disease
• Identify common psycho-social challenges in early stage for persons with Parkinson’s (PWP)
• Describe the symptoms and treatment of depression in Parkinson’s
• Identify how the person with PD impacts on the family caregiver and social network
• Discuss social work interventions for persons with PD and caregivers
Reactions to Diagnosis

- Reaction to the diagnosis is different for everybody
- A range of reactions that shift over time
- PD acts differently in different people which can lead to frustration

Reactions to Diagnosis

- How the news of the diagnosis is given has a powerful impact on how persons adjust to disease
### Reactions to Diagnosis

**Common reactions to diagnosis:**

- Anger
- Shock
- Fear
- Denial
- Anxiety
- Sadness and/or depression

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**Reactions to Diagnosis**

- Sense of loss can be an ongoing reaction for many, such as loss of dreams
- Grief over perceived losses: health, independence, sense of control, established roles, sexuality, daily routine, work life
Reactions to Diagnosis

Also consider:

- Personality resources/style, such as levels of optimism
- Body image—does identity revolve around capabilities of the body?
- Spirituality/philosophy about life

Depression in PD

Prevalence: about 50%
Range between 20-75% (differences due to methodological and diagnostic differences in studies)
Range: mild to severe
50% have major depression
50% other type of depression (dysthymia, bipolar, etc.)
Depression in PD

- Depression-- often unrecognized and untreated, sometimes it is the first symptom
- 65-75% depressive diagnoses are missed
- Movement symptoms traditionally defined PD
- Stigma-- about psychiatric illness

Depression in PD

dPD is associated with:
- excess disability; loss of income
- poorer outcomes,
- worse quality of life (QoL)
- exacerbates physical and emotional burden
- risk factor for psychosis and possible risk for cognitive impairments
- caregiver burden
Depression in PD

Persons with dPD tend to have:
• anxiety
• pessimism
• irrationality
• suicide ideation without suicidal behavior (this is being questioned)
• less guilt and self-reproach

Theories of causality:
• Reactive: secondary stress of having chronic illness
• Biological: results from neurodegenerative changes in PD
• Theories are not mutually exclusive
Depression in PD

Assessment of dPD is challenging due to:

• symptom overlap with core PD symptoms
  
  Such as: insomnia, psychomotor slowing, difficulty concentrating, fatigue, apathy

Depression in PD

• Use of psychotropic medications have not been sufficiently studied in dPD

• Some studies suggest that SSRIs can help without worsening the PD symptoms
Depression in PD

- Some prefer psychotherapy:
  - poor reaction to psychotropic meds
  - concern with side effects

- Some find that groups, including online groups are helpful

Apathy in PD

- Approx 30% of PWP develop apathy

- Reduced emotion, diminished motivation, lack of initiative, lack of concern, indifference

- Can be present from early on; not correlated to motor symptoms
Apathy in PD

- Apathy occurs with and without depression
- Difficult to differentiate from depression
- Caregivers are often the ones to complain about apathy, not PWP
- Treatment has been mainly via use of medications

Stress and PD

- Feeling stressed will aggravate PD symptoms
- Learning stress-management techniques is essential
Coping and Adapting

• Physical aspects of the disease do not correspond directly to subjective well-being.

• The strong belief in ability to control one’s adaptation to PD is associated with adaptive coping.

Frazier and Marsh, 2006, pg. 237

Coping and Adapting

Top coping strategies used by young-onset PWP:

• Exercise
• Being objective about one’s circumstances
• Taking one step at a time
• Being aware of one’s strength
**Coping and Adapting**

Top coping strategies used by young-onset PWP:

- Advocating for one’s self
- Maintaining sense of humor
- Being an active participant
- Engaging family support
- Educating others

Menza and Marsh, 2006, pg.245

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**Caregivers**

The often neglected person impacted by Parkinson’s disease
Caregiver Diversity

- Age of caregiver
- Life cycle tasks
- Relationship to patient
  - Spouse, partner
  - Adult child, siblings
  - Other family members, friend, neighbor
  - Social network
- Sexual orientation
- Ethnic identity/community connection

Life Cycle Concerns

- Position in the life cycle
- PD can interfere with successful completion of emotional challenges of the stage of the family
- Family with children and teens have different challenges than those with adult children
Caregiving Issues

Caregiver’s own reaction to diagnosis

- Shock and disbelief
- Denial
- Anxiety
- Worry, fear of the future
- Parallels PD patient’s reaction, but can differ. Difference can produce stress.

Parkinson Disease Specific Challenges

- The complex nature of PD and it’s treatment affects behavior/care needs
- This drives the care demands on the caregiver
- The unpredictability of PD creates stress
- Motor and non-motor changes have major impact

Lane, Hyer, Leventhal, 2005
### Caregiver Assessment

Multilevel assessment

**1) Personal resources**

- Health knowledge and beliefs
- Knowledge and skills related to caregiving tasks, problem solving ability, past experience in caregiving roles
- Stress tolerance/coping skills, resilience against burnout, stamina
- Motivation and satisfaction with caregiver roles and activities

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**2) Relationships and supports**

- Quality of past and current personal relationship with PD patient
- Marital satisfaction (mutuality)
- Adult children’s relationship to patient
- Availability of material resources/social support
- Quality of physical environment
- Assistance from family members
- Assistance from home health aides, others

Lane, Hyer, Leventhal, 2005
Caregiver Assessment

Additional factors:

• Financial factors that affect ability to hire personnel, purchase equipment
• Other life demands on caregiver
  - Outside job/occupation
  - Young children in the home
  - Disabled adult children, other family stressors

Lane, Hyer, Leventhal, 2005

Facilitating Communication

• Communication is crucial throughout the illness:
  establish good communication patterns in the early stages.
Facilitating Communication

Encourage relationship awareness:

- Help the person or couple focus attention on the relationship or an interaction pattern
- Encourage viewing the relationship as an entity
- Facilitate mutuality - the “we together” tackling PD

L. Acitelli & H. Badr, 2001

Coping with Chronic Illness

- Develop strategies
- Encourage communication – between couple and family members
- Identify resources
- Encourage connection to others - support groups, community--isolation is an enemy
Coping and Adapting

Resources significantly impact on the ability to respond to stressors

*Resources such as:*
- Internal abilities (creativity and intellect)
- External resources (finances and friends)
- Social supports are essential for coping
- Spiritual supports

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