Palliative Care in Parkinson’s Disease: Providing Patient Centered Care, Support, and Symptom Management

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Palliative Care

- Specialized medical care for people living with a serious illness (acute or chronic)
  - Parkinson’s Disease, Cancer, CHF, COPD, Kidney disease, Stroke, Dementia, ALS, and many more
- Focused on providing relief from the symptoms and stress related to the illness
- Goal is to improve quality of life for both the patient and family
- Based upon the needs of the patient and/or family
- Provided at any stage in a serious illness and can be provided along with curative treatment
Palliative Care vs Hospice

- **Palliative care**
  - Any point in a person’s illness
  - Diagnosis through end of life
  - Can be provided alongside active treatment
  - Pain/symptom management, psychosocial and spiritual support, advanced care planning

- **Hospice**
  - Medicare benefit
  - Must have qualifying diagnosis with life expectancy of 6 months or less
  - Must not be undergoing active treatment
  - Pain/symptom management, psychosocial and spiritual support, end of life care
  - Bereavement
Palliative care vs Hospice
Palliative Care Team

- **Provider (MD/DO, ARNP, PA-C)**
  - Pain and symptom management, discussions regarding goals of care, advanced care planning
- **Social Worker**
  - Psychosocial support, advanced care planning
- **Chaplain**
  - Spiritual and emotional support

- **Setting**
  - Inpatient, outpatient, community based
Provider (MD/DO, ARNP, or PA-C)

- Pain and symptom management
  - Nausea/vomiting, fatigue, constipation/diarrhea, insomnia, anorexia, etc.
- Goals of care
  - Facilitate complex discussions regarding a patient’s illness and decisions regarding care
    - Initiating hemodialysis, undergoing chemotherapy, surgery, tracheostomy, feeding tube, etc
  - All in the context of who they are, what’s most important to them, and what quality of life means to them
Social Worker (LICSW)

- Comprehensive psychosocial assessment
  - Participate in Goals of Care family meetings with interdisciplinary team
  - Continuous assessment of the whole person, their unique situational context and health status
- Provide continuity of support during transitions in hospital course
- Psychological support and counseling
  - Anticipatory grief and loss
  - Caregiver stress
- Discussions of advanced directives and healthcare POAs
- Resources and Transition Planning
Chaplain/Spiritual Care Provider (BCC-PCHAC)

- Support for spiritual needs
- Emotional, spiritual and existential distress
- End of Life
- Assistance in clarifying goals of care
Chaplain/Spiritual Care Provider (BCC-PCHAC)

- Having to come to terms with the changes that give meaning
- Questions about the meaning of life
- Concerns about relationships
- Worry about dying or death
- Issues related to treatment decisions
- Religious and Spiritual Struggle

(Fitchett, 2020)
Palliative Care in Parkinson’s Disease

- Complex symptom management
  - Pain, sleep disorders, fatigue, poor appetite, nausea/vomiting, depression, constipation, etc.

- Discussing goals of care
  - Patients, families, and clinicians work together to develop guidelines for current and future care.
  - Patients and families share their values, hopes, and fears, and clinicians provide information regarding diagnosis, prognosis, and guidance on medical treatments and resources
  - Issues addressed include what activities are most important to maintain quality of life and how the patient and family would like to navigate ongoing or increasing levels of patient dependence
    - “How do you define quality of life?’
    - “What do you enjoy or look forward to?”
    - “What is the toughest part of this?”
    - “What are you most afraid of?”
Challenges for Individuals with Parkinson’s Disease

- Isolation
- Changes in family roles
- Loss of independence
- Changes in self-identity
- Changes in relationship dynamics
- Fear of losing love from primary caregivers (if spouse/significant other)

(Risk, 2013)
Spiritual Issues that may Accompany Parkinson's Disease

- Religious and Spiritual Struggle
- Self-blame
- Guilt/Shame
- Forgiveness/Reconciliation
- Issues of adaptation

(Risk, 2013, Greenstreet, 2006)
Palliative Care Spiritual Care for Parkinson's Disease

- Strengthening the “spiritual self”
- Refocus on the “inner self” to cope with physical decline
- Narrative storytelling
  - “Step out” and share story of illness
  - Integrate realities of disease and related losses into new understandings of meaning and purpose
- Encourage connection (loved ones, community, faith/spirituality)
- Creative expression
Depression

Both depression and anxiety are very prevalent in PD (Hassan et al., 2012), negatively affecting health-related quality of life for both the PWP and care partner.

Non-motor symptoms, particularly depression and anxiety (among others), significantly affect patient and caregiver quality-of-life (QOL), often even more than PD motor impairment (Erickson & Muramatsu, 2004).

Difficult to diagnose: symptoms of Parkinson's can mask symptoms of depression.

Embarrassment, stigma, isolation, self-esteem, self-image, social activity and relationship changes for both patient and caregiver.
What can a social worker do for a person with Parkinson's Disease and their family?

- Interdisciplinary collaboration for continuity in patient care
  - The social worker’s comprehensive psychosocial assessment of the individual’s total situation, including stressors, strengths and available social supports for a holistic, all-inclusive picture

- Supportive counseling

- Provide access to resources to encourage medication adherence

- Resources and transitional planning

Palliative Care in Parkinson’s Disease

**How can I access Palliative care?**

- Ask your neurologist, primary care provider, or other specialist for a referral
- [https://getpalliativecare.org/](https://getpalliativecare.org/)
References

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Thank you!