

Caregiving and Psychosocial Issues in Parkinson's Disease

**Elaine Lanier, RN, MS
PADRECC
San Francisco Veterans Affairs**

Parkinson's Disease & Caregivers

- ▶ PD is a chronic, progressive neurological disease, characterized by tremor, rigidity, bradykinesia, & postural instability.
- ▶ PD prevalence is projected to affect 1.3 million by 2040 (Lilienfeld & Perl, 1994)
- ▶ Only about 7% of PD persons are admitted to long-term care facilities; most are cared for by families at home (Mitchell, Kiely, Kiel, & Lipsitz, 1996)

Who are Family Caregivers?

- ▶ Those who provide a wide array of care to chronically ill or disabled relatives or friends in the home
- ▶ Can be wife, husband, daughter, son, grandchild, close friend, neighbor
- ▶ Majority are women, primarily wives (Rabins, Lyketos, & Steele, 1999)
- ▶ Spousal caregivers usually elderly & may have own medical conditions.

Who Are Family Caregivers? (Cont.)

- ▶ Provide 80% of chronic illness home care services to persons age 50 and above
- ▶ Provide daily care including
 - Medication management
 - Symptom management
 - Hands-on care
 - Emotional support
 - Davis, 1996; Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000)
- ▶ Are important and valuable to the care of the PD patient

Value of PD Family Caregivers

► To the Clinician

- Enhance communication between patient and clinician
- Assist with adherence to medication and device regimes
- Help organize and coordinate medical care
- Provide a more objective reporting of symptoms
- Remind and reinforce instructions
- May be more reliable than patient
- Can be the, “voice of reason”

Value of PD Family Caregivers (Cont.)

► To the Clinician

- “Caregivers are famously active online and keep track of so much of what's going on in the media (in support groups, chat rooms, and in the lay press, etc...)”
- “They are often our "eyes and ears", being the first person that makes us aware of the new hot topics that people are talking about...”
- They help with transfers in the clinic
- They are the, “Resource generator,” (find the help)

Clinicians & PD Caregiver

- ▶ Include PD caregiver in treatment plan, education & all aspects of patient's care
- ▶ Understand the caregiver role
- ▶ Help with caregiver issues



Understanding the PD Family Caregiver Role

- ▶ Help with ADLs, medication management & administration, household chores, financial management, transportation, emotional support, medical plan management
- ▶ Cope with nonmotor symptoms (Depression, anxiety, sleep disturbance, dysphagia, sexual dysfunction, etc.), can be more difficult than motor symptoms
- ▶ Role is demanding, a 24-hour job 7 days per week & duties increase with advancement of disease

Stresses of PD Caregiving

- ▶ Caregivers often ill equipped to manage the emotional & physical demands of caregiving
- ▶ Face increasing demands due to PD progression
- ▶ Have their own aging processes & physical decline
- ▶ Caregiving can place constraints on
Social & family life
Employment & finances



Caregiver Burden

- ▶ The degree of caregiver's awareness that their own health, socialization, & financial situation is being adversely affected due to caregiving obligations (Rabins et al., 1999).
- ▶ Research has shown family caregivers often experience:
 - Stress
 - Depression
 - Compromised physical and psychological health
 - Premature mortality
 - (Aranda, 1997; Bodnar & Kiecolt-Glaser, 1994; Mastrian, Ritter, & Deimling, 1996, Rose-Rego et al, 1998; Schulz & Beach, 1999)
 - Caregiver suicide has been reported

How to help the PD Caregiver

- ▶ Be aware of caregiver needs
- ▶ Provide ongoing education & support to patient and caregiver
- ▶ Refer to:
 - Support Group for Caregivers
 - Mental Health Services/counseling
 - Social Services
 - Provide information on community services, financial information, and end of life care

Encourage PD Caregiver To:

- ▶ Maintain their own health
 - Make & keep medical, dental appointments
- ▶ Take breaks (get-a-ways & mini-breaks)
- ▶ Get their sleep (even if PD person can't)
- ▶ Make & keep social & Spiritual
- ▶ Keep (or develop) sense of humor



How to help the PD Caregiver



- ▶ Get help!
 - From family, neighbors, friends, church, synagogues
- ▶ Benefits
 - Lessen feelings of isolation
 - Helps get those needed breaks
 - Gives more confidence

Advanced Parkinson's Caregiving



- ▶ Home Health & Respite care
- ▶ Care outside the home
- ▶ Hospice Care

Home Health & Respite Care

- ▶ Home Health
 - VA programs:
 - Homemaker Home Health Aide
 - Aid and Attendance & Housebound through VA Pension program
www.vba.va.gov/bln/21/pension/vetpen.htm
 - Medicare
 - Requires 3 day hospital qualifying stay
 - RN, PT, OT, nurse aid services
- ▶ Respite
 - Temporary care of patient in nursing home
 - SFVA provides 12 days, twice/year, no cost
 - Caregiver & patient both get needed break

Care out of the home

- Difficult decision for both caregiver and PD patient
- Not a failure of caregiver
- Realization that care required is beyond what caregiver can provide
 - Caregiver can no longer:
 - Perform physical tasks, i.e., lifting, pulling, turning, incontinence care, protection from falling, etc.
 - Handle emotional problems, i.e., dementia, psychosis, sleep disturbance
- Caregiver remains caregiver but level & type changes
- Caregiver becomes patient advocate & overseer of care provided

Options for care out of home



- ▶ Continuing Care Retirement Community
 - Covers all levels of care but expensive
- ▶ Assisted Living Facilities
- ▶ Board & Care--usually small, more personal
- ▶ Nursing homes

Hospice Care

- ▶ Hospice: interdisciplinary group of skilled professionals trained to support the PD patient and their family through end-of-life care and bereavement services (Foley & Carver, 2001)
- ▶ Care provided in home, nursing home, assisted living, hospital
- ▶ Services paid for by Medicare Part A
 - VA will pay if patient doesn't have insurance
- ▶ MD must determine PD patient has 6 months or less to live—difficult for MD & caregiver
- ▶ Introduce idea before caregiver is too exhausted

Local & Community Resources for Caregiver

- ▶ Free to low cost: Neighbors, friends, churches, synagogues, senior centers, adult day health, Meals on Wheels, door-to-door vans
- ▶ Fee based: In-home care (help with cooking, bathing, dressing, meal prep, etc.)
- ▶ Social Worker from health plan or hospital

Online Resources

- ▶ Family Caregiver Alliance: San Francisco
 - www.caregiver.org
- ▶ National Family Caregivers Association
 - www.thefamilycaregiver.org
- ▶ American Parkinson's Disease Association
 - www.apdaparkinson.org
- ▶ National Parkinson's Association
 - www.parkinson.org
- ▶ Michael J. Fox Foundation
 - www.michaeljfox.org
- ▶ Each website gives more sources & other websites

The Results

