

The Role of Palliative Care in Parkinson's Disease

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Typical **Early PD** Visit

- Diagnosis
- Patient/family education
 - What is PD?
 - What is my prognosis?
- Starting treatment?
- Dopamine agonist vs Levodopa?
- Counseling on exercise, etc...?

Typical **Moderate PD** Visit

- Complications of dopaminergic therapy
 - Wearing off
 - Dyskinesia
 - COMTI's, MAOI's, Amantadine, DBS
 - Other med side effects
- Increasing Non-motor Sx
 - Cognitive impairment, depression, sleep, ANS
- Increasing role for multidisciplinary services:
 - PT, Sp/Sw, psychiatry, etc...

Typical **Advanced PD** Visit

- Increasingly dependent for many/all ADLs
 - Immobility
 - Dementia
 - Incontinence
 - Etc...
- Limitations on previously effective tx
- As a neurologist, one might think...

“What is my role now?”

Overview

- Definitions and changing scope
- Review of the palliative care literature in PD
- Role of palliative care across the PD spectrum
- Our developing efforts at the SFVA PADRECC

**DEFINITIONS,
CHANGING SCOPE**

Definitions

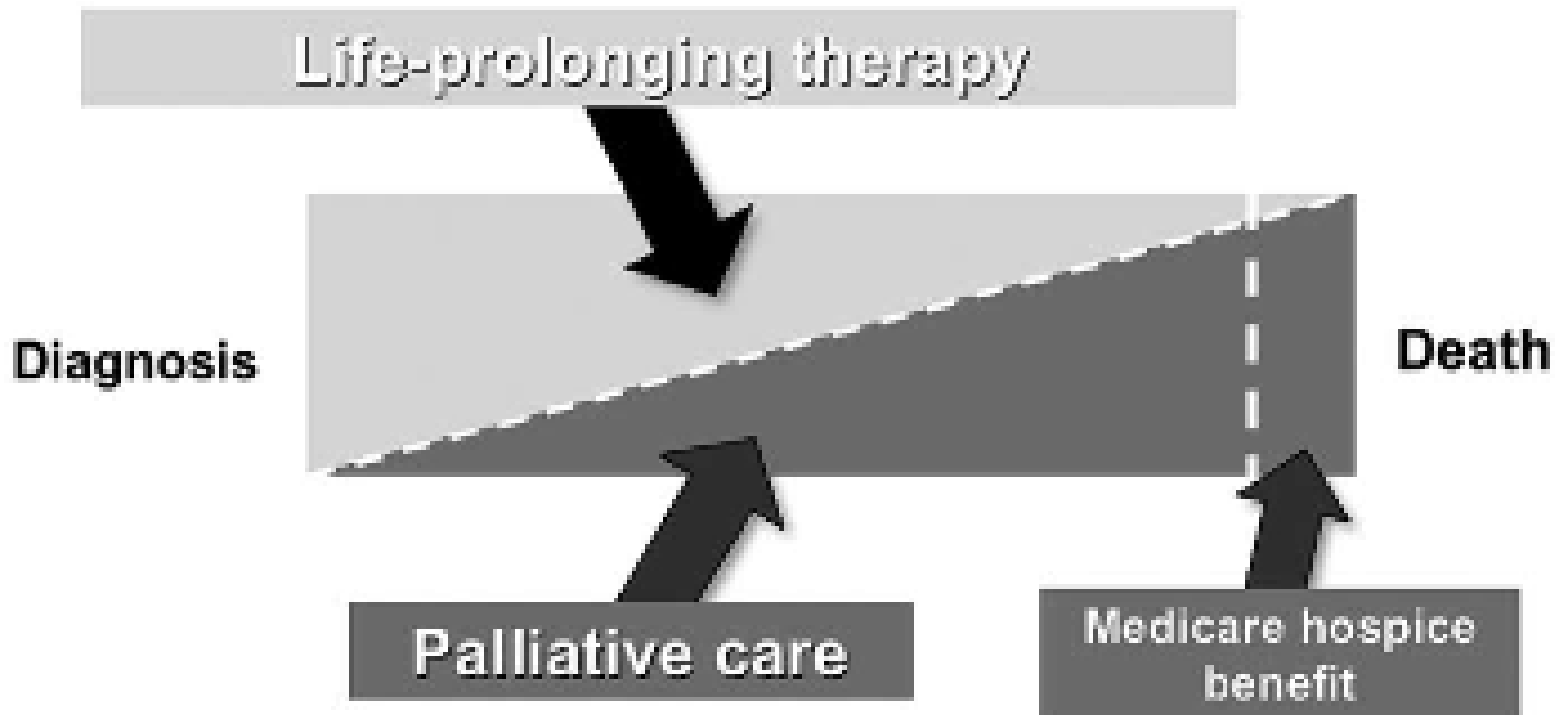
- Palliation: from the Latin *palliare* = to cloak or conceal
 - Treatment directed at relieving symptoms, rather than curative or life-extending treatments
- WHO definition of Palliative Care (2002):
 - “an approach that improves QOL of individuals and their families facing problems associated with life-threatening illnesses, through the prevention and **relief of suffering** by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.”
 - an approach that “affirms life and regards dying as a normal process”... “neither hastens nor postpones death”, ... but relieves “pain and other distressing symptoms.”

Changing Scope of Palliative Care

- Moving *away* from a restricted focus on:
 - Terminal stage of illness/end of life
 - Malignant diseases
- Moving *toward* a broader focus:
 - Across disease spectrum
 - Broader range of serious medical illness

Changing Scope of Palliative Care

Chronic Care (on one side)



Hospice Care (on the other)

Definitions


- Chronic Care
 - Treatments that are curative or seek to extend life
 - Chronic diseases make up > 70% of deaths in U.S.
- Hospice (PDF)
 - “a program of care designed improve QOL through pain relief and symptom management for individuals who are facing the **end of life**”, including bereavement services

PALLIATIVE CARE AND PD

Palliative Care and PD

- Is PD a condition that would benefit from PC?
- PD #2 neurodegenerative disease (after AD)
 - 2% of those > 80 years old
 - 10% of those in nursing homes
- All familiar that it causes significant morbidity, disability, motor and non-motor

CDC Leading Causes of Death 2006

- Life expectancy at birth was 77.7 years.
 - The 15 leading causes of death in 2006 were:
 1. Diseases of heart (heart disease)
 2. Malignant neoplasms (cancer)
 3. Cerebrovascular diseases (stroke)
 4. Chronic lower respiratory diseases
 5. Accidents (unintentional injuries)
 6. Diabetes mellitus (diabetes)
 7. Alzheimer's disease
 8. Influenza and pneumonia
 9. Nephritis, nephrotic syndrome and nephrosis (kidney disease)
 10. Septicemia
 11. Intentional self-harm (suicide)
 12. Chronic liver disease and cirrhosis
 13. Essential hypertension and hypertensive renal disease (hypertension)
 14. Parkinson's disease 
 15. Assault (homicide)
- PD #14 overall
 - First appeared in top 15 in 2003
 - 19,000 deaths total (1/3 over 85)
 - 0.8% overall

Palliative Care and PD

- But most literature states PD *not* cause death
- Kinsley (PD patient) in *New Yorker* ...
 - “one of the first things you are told... is that you are not likely to die from PD”
- Very few studies on how PD patients die

Much about PD *not* typical for PC

- Not thought of as directly leading to death/terminal illness
- Course is relatively slow
 - even spread out over decades
- Variability in symptoms, trajectory makes prognosis difficult
- --

But much PD *is* typical for PC

- No cure
- Almost all treatment symptomatic, yet...
 - Lack of focus on suffering (pain, depression, fatigue all very common)
- Social/emotional aspects frequently cited by patients as worst aspects of PD, and are major determinants of QOL
- Caregivers report significant burden
 - anxiety, financial, physical → “burn out”

Research Lacking

- Limited research, mostly observational
- Little known about what patients perceive about PD (body image, immobility, social role) or their perceived needs
- Even less evidence-based medicine

- AAN Ethics and Humanities Subcommittee, 1996:
 - “because many neurologic illnesses are progressive and incurable, the optimal care of such patients requires that neurologists understand and apply the principles of palliative medicine.”

General Principles of Palliative Care

- Patient and family are the unit of care
- Multi-disciplinary coordinated approach
- Treatments focused on how pt feels:
 - Suffering: pain, depression, anxiety, burdens, etc..
- Education, support, services

General Principles of Palliative Care

- Adjusts focus of curative/chronic care
 - Failure to acknowledge limits of medicine
 - Avoidance of over-aggressive treatments
 - Quality of life
 - Symptoms and how they relate to pt/family goals
- NOT in place of curative/life-prolonging
- NOT prognosis dependent
- NOT solely about end of life (not hospice)

Goy et al, PD c/w ALS

- **OHSU/Portland PADRECC surveyed PD and ALS caregivers about pt's last month of life**
 - Symptoms, degree to which sx bothered pt
 - Use of health care services
 - Overall goals of medical care
 - Degree to which wishes were met/respected
- Strategy: to show PD end of life is similarly troublesome as ALS, so as to bring attention to needs of PD patients at EOL

Goy et al 2008: PD c/w ALS

- Many similarities, but **PD less prepared, and PD received less palliative care**
 - Difficulty eating #1 complaint for both PD, ALS
 - Other physical complaints very similar
 - Pain prominent at similar levels (40-50%)
 - But PD pts more frequently untreated
 - PD had *higher* level of confusion, dementia

Goy et al, PD c/w ALS

- ALS: more frequently:
 - could state their EOL care goals
 - met their EOL care goals
 - used hospice care
- PD: higher importance on comfort care, and less importance on extending life

Goy et al, PD EOL

- Use of Health Services
 - 53% used hospice, (median 2.5 weeks)
 - 36% used home health, (median 8 weeks)
 - 43% used private aide, (median 26 weeks)
- Pain meds more likely to be given if in hospice or SNF

PD vs Other Palliative Dx's

- Comparison with ALS
 - Even in mild ALS, palliative care more immediate
 - Specialist ~ certain that pt will die from ALS
 - This is not so for more PD (especially younger, stable, slower PD)
 - But most neurologists don't think of PD pt with dysphagia as palliative care candidate

Hudson et al 2006:

- Asked: “Would people with PD benefit from palliative care?”
- Performed structured interviews in 35 people affected by PD (8 patients, 21 caregivers, 6 professionals) in Australia
- Describe the experience of PD
 - Support, practical issues, needs/recommendations

Hudson et al: 5 Prominent Themes:

- 1. Emotional Impact (grief w/dx, fear of px)
 - Feeling of loss and fear of the future
- 2. Staying Socially Connected (!!!)
- 3. Financial hardship (work, care, home mod.)
- 4. Physical challenges (FOG, ADLs, transport)
- 5. Finding help for advantaged stages
 - Lack of interventions, skilled professional, settings
 - Support groups, counseling, respite, specialist clinics
 - *Multidisciplinary expertise, and extensive networking*
 - Concern/fear about inpatient settings (staff's lack of knowledge and competence with PD)

Hudson et al, 2006

- Conclusions:
 - PD very similar to more typical diseases in which palliative care is prominent (malignancy)
 - Grief and Fear, Social isolation, financial hardship, caregiver burden, need for respite...
 - Major difference: Not usually considered a “terminal disease”
 - *PD patients “may not wish to see themselves as terminal,” so how care might best be offered is difficult*

Lanoix 2009

- Managing the Chronic-Palliative Interface
- When and how do we initiate the palliative care discussion?
- Difficult to negotiate starting PC, as can be slow/decades long, and symptomatic tx can let patient live well for long time

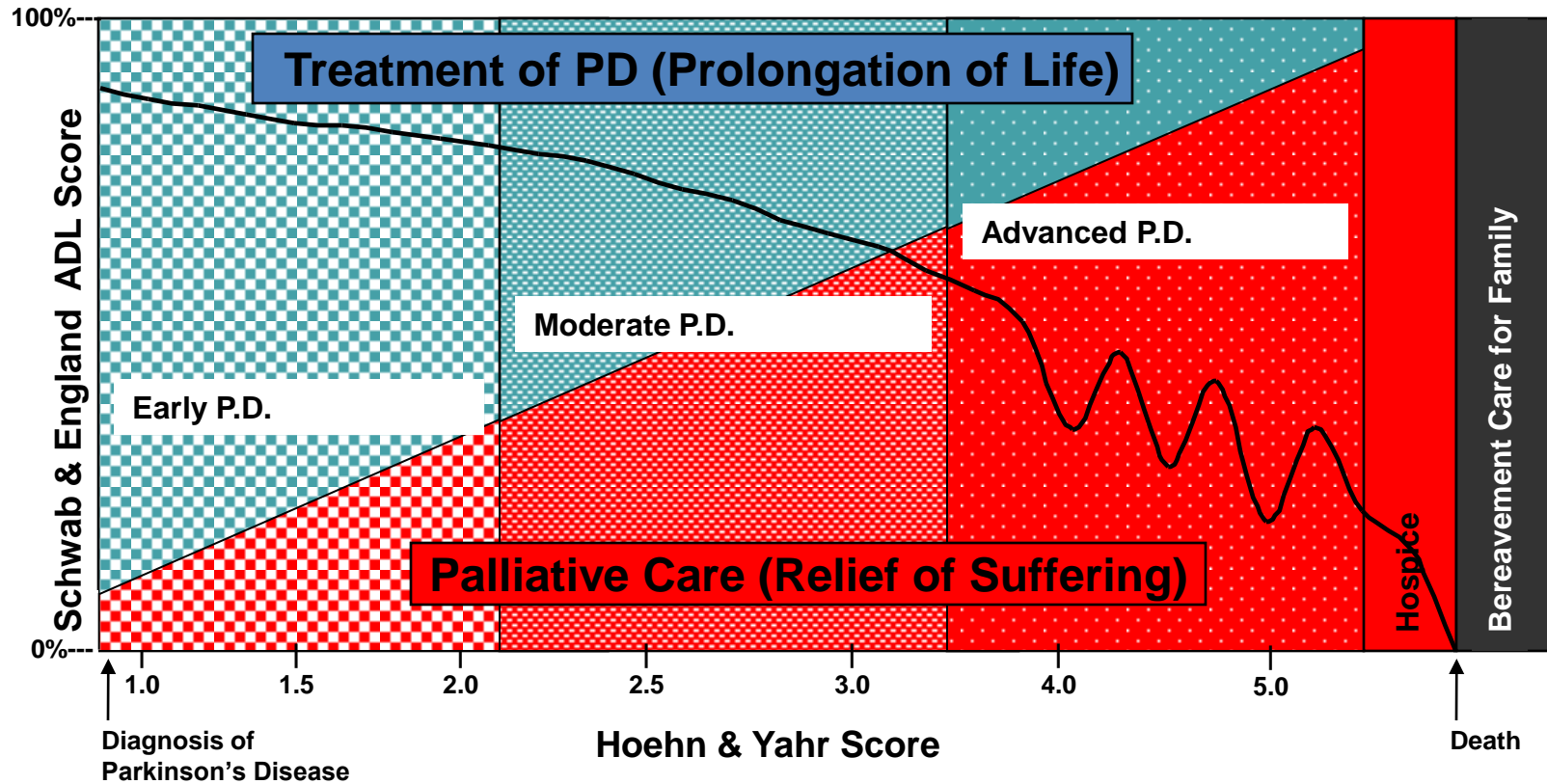
Lanoix 2009

- Chronic Care/Palliative Differences
 - Goals focused
 - Facilitate better EOL
 - Dr/Pt (autonomy) → Dr/Pt/Caregiver Relationship
 - Chronic care focused on patient autonomy and sometimes ignores contributions/burden of caregiver
 - Family/caregivers are recipients:
 - Recognition, care services, training, compensation

PC in PD: Across Disease Spectrum

- Bunting-Perry 2006
- Argues for an early application of palliative care principles, and continuation through entire disease course
 - “from diagnosis to hospice”
- Stresses Legal aspects (POA...), advanced care planning
- Struggle when to start discussion
- Continuous focus on communication, goals

Models of Care Across the PD Spectrum



Adapted from Bunting-Perry 2006

Early PD Palliative Care

- Cognition/capacity intact: Good time to discuss POA, advanced directives...
- Remember QOL issues
- Screen non-motor and psychosocial stresses
 - Depression/anxiety, sleep, pain
- Each patient is different:
 - Some are planners (want to know in detail)
 - Some need reassurance/hope

Moderate PD Palliative Care

- Increased non-motor symptoms
 - Although great variability
- ADLs becoming more affected
 - PT/OT
 - Begin to screen caregiver (as now more burden)

Advanced PD Palliative Care

- Palliative care replaces life-prolonging tx
- Education about palliation vs hospice
- Advanced care planning to the forefront
- Co-mgmt with palliative care/geriatrics
- Non-motor becomes focus
 - Constipation, dementia, psychosis
 - May need to *decrease* dopaminergic tx
- “Episodes” of worsening, exacerbations with more inpatient admissions

PD EOL and Hospice

- 70% of Americans die in hospital (life-prolonging measures)
- Only 15% in hospice (half are cancer pts)
- Advanced directive (if in place) used to transfer care to hospice team
- Artificial nutrition/hydration, DNR, DNH, comfort-care only, pain mgmt
- Hospice paid for by Medicare A (home/inpt)
- 3 Criteria (6 mos to live, accept hospice care, not curative, at Medicare-approved pgm)

Bereavement Care

- Caregiver exhaustion, depression
- Caregiver role is finished
- Socially isolated, little support

- Help reorganizing roles/lives

- Medicare 1 year of bereavement services
- But also religious and NPOs

Developing Efforts at the SFVA PADRECC

PADRECC

- PADRECC = Parkinson's Disease Research Education and Clinical Center
- Mandated by Congress, 2001
- 6 centers of excellence within the VA system
 - SF, LA, **Portland, Phila.**, Houston, Richmond
 - 2006 Consortium Center Network (~50)
- Provide multi-disciplinary care for 40,000 veterans with Parkinson's disease and related diseases

Change in PADRECC Demographics

- WWII generation has gone into their 80s/90s over the last decade
- Many WWII PD patients (and now Korea and Vietnam vets as well) have entered advanced stages of PD
- PADRECC clinics increasingly focused on advanced PD issues

PADRECC Advanced PD Clinic

- Advanced PD patients shifting care needs
 - Much more time for counseling and detailed discussion of psychosocial needs, non-medical needs
 - Much effort in arranging consults, coordinating with PMD/Geriatrics
 - Much more time arranging home care, PT, respite, placement and other services

PADRECC Advanced PD Clinic

- Advanced PD patients to consider...
 - Prominence of Non-motor symptoms
 - Dementia, psychosis, VH, delusions
 - ANS: OH requiring lower doses of meds, incontinence
 - Dependent for most ADLs
 - Toileting, feedings, managing meds
 - Dysphagia, weight loss
 - OOB/OOC
 - Gait/balance/falls
 - Medical co-morbidities
 - BP, DM, CAD, OA...
 - Recurrent Infections/UTIs...

PADRECC Advanced PD Clinic

- VA system allows for an approach that easily integrates multi-disciplinary care
 - Geriatric Pharmacist works closely w/us
 - Geriatrics fellows rotate through clinic
 - Social Worker readily available
 - Physical Therapist (including home PT)
 - Neuropsychologist
 - Nutritionist
 - Speech Pathology/Swallow Evaluations

PADRECC Advanced PD Clinic

- Concentrate Advanced PD patients on one clinic per month (first Tuesday)
- Above listed disciplines can be on hand or readily available if issues arise

PADRECC Advanced PD Clinic

- **Evaluate caregiver**

- Awareness, perceptions of advanced PD, PC
- Discussed of LTC options, PC, Hospice
 - Transition from chronic care → Palliative care
 - Discussion of end of life goals
- Emotional and physical demands
- Anyone helping?
- Ability to manage, cope, depression
- Emotional physical demands, emergencies, death
 - Need for SNF placement?
- Assess burden, stress, burn-out: need for respite

Much to Offer...

- SW consult (adv.dir, DPOA, legal, benefits, placement, CLC/SNF/Yountville)
- Respite (2 weeks every 6 months)
- New PMD/Geriatrics/HBPC referral if needed
- Home PT
- Hospice referral
- Chaplain referral

Conclusions

- PD under-recognized as:
 - As cause of death
 - Amenable to principles of palliative care
 - In advanced PD
 - But also across PD spectrum (especially as focus of the palliative care field shifts as well)
- Question of resources and coordination
- Much to offer...

THANKS.