

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 ADLs
 - Immobility, falls
 - Dementia, depression, psychosis
 - Incontinence, lightheadedness
- Limitations on previously effective tx
- As a provider, one might think...

...“What is my role now?”

Overview

- Advanced Parkinson's disease (PD)
- Principles of Palliative Care
- Palliative Care for PD
- Our efforts at the SF PADRECC

ADVANCED PARKINSON'S DISEASE

Advanced PD

- PADRECC demographics: Many veterans from WWII, Korea, Vietnam with PD have progressed to *advanced* stages
- Different care needs
 - Previously effective PD treatments do not address (and frequently exacerbate) most disabling (non-motor) symptoms
 - Increasing psychosocial, financial stress on pt/cg
- Typical PD clinic not focused on these needs

Advanced PD

- PD is incurable, under-recognized cause of death
- Caregiver burden can be severe
- Prognosis is often inaccurately communicated
- Palliative/Hospice services under-utilized
- Standard PD clinics frequently inadequate
- QOL suffers
- ... PADRECC model is ideally suited to address these needs

PRINCIPLES OF PALLIATIVE CARE

Definitions

- Palliation: from the Latin *palliare* = to **cloak** or **conceal**
 - Treatment directed at relieving symptoms
 - (rather than curative/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.”

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

What is Palliative Care?

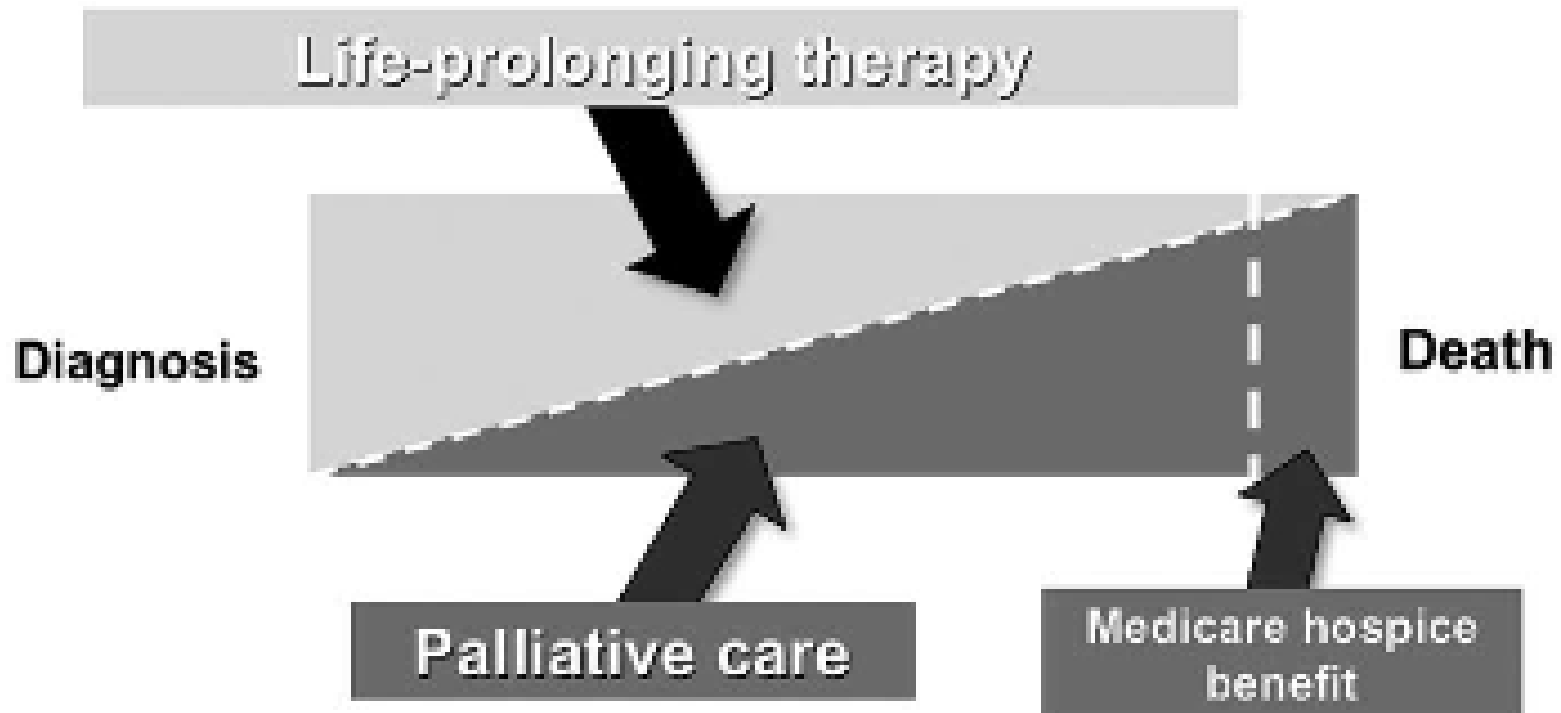
- Adjusts Focus of Chronic Care:
 - Relief of suffering (pain, depression...)
 - QOL >>> Cure
 - Patient/Caregiver/Family as unit of care
 - Multi-disciplinary, proactive/planned
 - Focus on Goals of pt/family
 - Symptoms
 - Education, support, resources, services
 - Avoidance of aggressive tx/side-effects
 - Acknowledges limits of medicine

Palliative Care is **Not** Hospice

- Can be applied earlier/across the disease **spectrum**, as it is...
 - **NOT** prognosis-dependent (not just EOL)
 - **NOT *just*** for terminal, malignant illnesses
 - **NOT** in place of life-prolonging therapies
- It is **not** “giving up”
- Actually, in every sense, it is a **formal expansion** of care

Changing Scope of Palliative Care

Chronic Care (on one side)



Hospice Care (on the other)

PALLIATIVE CARE AND PD

Palliative Care and PD

- Would PD patients/families benefit from PC?
- PD #2 neurodegenerative disease (after AD)
 - 2% of those > 80 years old
 - 10% of those in nursing homes
- Significant morbidity, disability,
 - Motor: tremor, stiffness, slow, gait disturbance
 - Non-motor: cognitive/behavioral, ANS, ...

Much about PD *not* typical for PC

- Not routinely thought of as a terminal illness
- Prognosis difficult:
 - Course is relatively *slow* (even decades)
 - Course is highly *variable*
 - Symptoms
 - Trajectory

*Much about PD is ***classic*** for PC

- Incurable
- All treatment is symptomatic (*palliative*)
 - yet, lack of focus on suffering
- Significant caregiver strain
- Social/emotional aspects are frequently large detriment to QOL
- In advanced PD, treatment (especially if aggressive) can exacerbate disabling sx

Barriers to Palliative Care in PD

- Differences in Attitude, PD vs ALS (Liao 2007)
 - ALS considered “terminal”, PD “chronic”
- ALS more predictable, rapid course (3-4 yrs)
- PD highly variable, slower course (~decades)
- ALS has hospice criteria (PD?, not specifically)
- Contradictions: CDC lists PD as #14 cause of death, yet NIH states “PD is not by itself a fatal disease”

Barriers: PD as a Cause of death?

- 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

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

Barriers: Research is 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.”

“Would people with PD benefit from Palliative Care?” (Hudson 2006)

- 5 Themes in Patient/Caregiver Surveys:
 - Emotional impact of diagnosis
 - Staying socially connected
 - Enduring financial hardship
 - Finding help for advanced stages
 - *Managing physical challenges*

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*

PD c/w ALS (Goy/Carter 2007, 2008)

- Interviewed caregivers of PD/ALS pts about their final month of life
- Most complaints very similar:
 - Difficulty eating #1 complaint for both PD, ALS
 - Other physical complaints very similar
 - Pain prominent at similar levels (40-50%)
 - But PD pts' pain more frequently untreated
 - PD had *higher* level of confusion, dementia

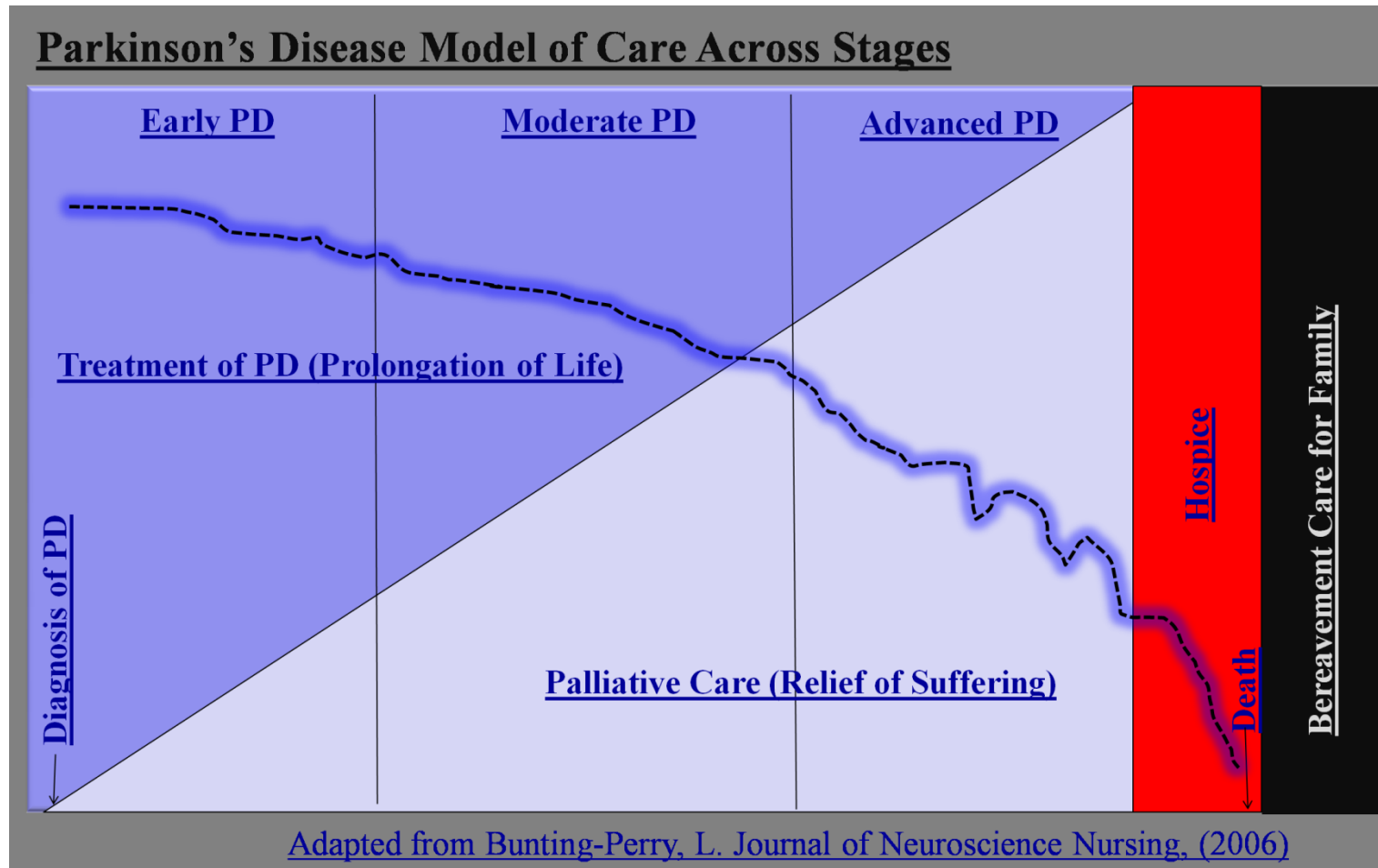
Goy et al 2008: PD c/w ALS

- Many similarities, but **PD less prepared, and PD received less palliative care**
 - ALS patients:
 - more accepting of death
 - aware of prognosis, and at peace with death,
 - received more hospice (more commonly, and for longer duration)
 - could state their EOL care goals, goals were met
 - PD patients:
 - Placed higher importance on comfort care, and less importance on extending life > ALS
 - despite equal ability to state goals: 25% still received feeding tube, 30% breathing support

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

PD Progression and Model of Care



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 chronic care model, and eventually 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

Bereavement Care

- Caregiver exhaustion, depression
- Caregiver role has ended
- Socially isolated, little support
- Help reorganizing roles/lives
- Medicare 1 year of bereavement services
- But also religious and NPOs

OUR EFFORTS AT THE SF 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

- Many WWII PD patients (and now Korea and Vietnam vets as well) have entered their 80's, 90s, and advanced stages of PD
- PADRECC clinics increasingly focused on advanced PD issues
- Shifting care needs, more time/effort for:
 - counseling/detailed discussion of psychosocial needs
 - arranging consults, coordinating with PMD/Geriatrics
 - arranging home care, PT, respite, placement and other

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 (occ.)
 - Social Worker readily available
 - Physical Therapist (including home PT)
 - Neuropsychologist
 - Nutritionist
 - Speech Pathology/Swallow Evaluations

PADRECC Advanced PD Clinic

- Dedicate one clinic per month, to give more time to advanced PD patients
- Above listed disciplines can be on hand or readily available if issues arise

SCREENING: referring if...

- Prominence of Non-motor symptoms
 - Dementia, psychosis, VH, delusions
 - ANS: OH requiring lower doses of meds, incontinence/toileting
 - Pain
- Dependent for most ADLs
 - Feeding: meals, wgt loss, dysphagia
 - Mobility: falls, freezing, transfers OOB/OOC
 - Managing meds
 - Social: financial, housing, caregiver strain
- Reduction of Meds to avoid side effects
- Significant Co-morbidity
 - Recurrent Infections (esp UTIs, aspiration...)
 - ER visits, hospitalizations

Advanced PD Clinic: “Intake”

- Nurse, chaplain begin with patient, family:
 - Screen high-risk sx, screen caregiver
 - Clarify goals, wishes
 - Discuss advanced directives
- Team meets to prioritize needs, goals, plan
- SW search for resources
 - Disability, financial, service connection
 - home-based care, housing, placement
- Referrals: PT, OT, Speech/swallow, nutrition, hospice

PADRECC Advanced PD Clinic

- **Evaluate caregiver**

- Sleep, physical strain, emotional demands*
- Social confinement, family adjustments, changes in plans*
- Financial strain, work change*
- Coping/Managing?, Overwhelmed?
- Anyone helping?
- Awareness, perceptions of advanced PD, PC
- Emotional and physical demands, burden/stress/burn-out
- ?? Need for Respite, SNF placement

*based on Modified Caregiver Strain Index

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: spiritual care
- Time***

Results: first 18 months

- Referred 23 male veterans to our PCC
- Age: 64-90, mean 77 years
- Duration: 4-25 years
- 20 PD, 2 PSP, 1 MSA
- Five no-shows to clinic
 - 3 admissions (falls, FTT)
 - 2 deaths

Results: first 18 months

- (+) reduced ER visits, hospitalizations
- (+) subjective reduction in caregiver strain
- (+) appropriate resources (expedited placement, disability apps, etc...)
- (-) need for more proactive referrals
- (-) need to improve continuity of f/u (travel difficulties, poor health evolves quickly)
- (-) not objective: submitting IRB

Conclusions

- PD under-recognized as being 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)
- Much to offer...

Conclusions

- Palliative Care in PD, Provides Mechanism to:
 - Initiate difficult discussions
 - Make decisions in careful, thoughtful way (instead of rushed, during stressful/poor health)
 - Aggressively recruit resources when needed
 - Foster integration, coordination
 - Focus on caregivers, family
 - Complete the “comprehensive care” goal of PD centers

THANK YOU.